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ABSTRACT

This project investigated the different perspectives of families from diverse backgrounds on augmentative and alternative communication (AAC). The transcripts from the focus groups and individual interviews at five national sites conducted from December 1995 to August 1996 are provided. The following focus groups were held: (1) family involvement with AAC devices; (2) parents of children using AAC devices; (3) related services personnel working with Navajos; (4) vendors of AAC devices; (5) related services personnel; (6) families without AAC devices; (7) families with AAC devices; (8) vendors of augmentative communication; (9) parents having AAC devices; (10) Vietnamese parents of children with disabilities; (11) Chinese families of children with disabilities; (12) Hispanic families with AAC devices; (13) Hispanic families without AAC devices; and (14) related services personnel servicing predominately Hispanic/Latino populations. Transcripts are also included of structured interviews with Navajo families, family members of a child without an AAC device, a Dutch family of a child with a disability; and an African-American family with a child with a disability. Each transcript is prefaced by background information and synthesis statements. Appendices include assessment forms and specific questions for professional and family groups. (CR)

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ED 424 705

Culture, Families, and Augmentative and Alternative Communication (AAC) Impact:

A Multimedia Instructional Program for Related Services Personnel and Family Members

Focus Group and Structured Interview Approaches and Proceedings, 12/20/95-8/15/96

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October 26, 1998

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Research Background

The focus groups and individual interviews for this project were arranged and conducted by Moderators at each of five national sites (Arkansas, California, Illinois, Missouri, New Mexico). The Moderators were provided training regarding cultural sensitivity to enable them to be responsive to the unique cultural needs of each participant. Moderators were asked to: (a) conduct and videotape 1-2 hours for additional data and CD-ROM production, (b) ask participants to complete questionnaires, and (c) secure consent forms.

Preparing for Data Collection

Each Moderator prepared in different ways to conduct the focus groups and interviews. In some cases the researchers worked through community liaisons or advocates to develop trust and rapport to gain entrance into a targeted community. In some cases interpreters were used. Moderators were sensitive to such cultural symbols as colors worn; in a large inner city colors could not be worn that were used by gang members, while on a Navaho reservation, colors also had special meaning. Interviews were arranged at times and locations convenient for family members. Researchers were respectful of the time, space and reciprocity issues for each cultural group who participated. All families received a small stipend or gift certificate for food.

Changes in Data Collection Process

Researchers balanced the need to maintain adequate research stability and integrity of protocol and procedures with respect for difference in family culture and comfort levels. It was a balance between gaining the family "voice" with the research agenda. Not all families were comfortable with focus groups, so individual interviews were conducted. In European American interviews, for example, family members were more comfortable with demographic and AAC questionnaires. In other families, they were fearful of "government" and were less comfortable with giving demographic information or completing questionnaires. On a Navaho reservation, for example, one researcher spent several hours developing rapport and trust and was honored to be invited into a home for an interview. In this situation, videotaping and extensive questionnaires were not appropriate. In some situations, researchers felt that questionnaires inhibited the participant's willingness to speak; in these situations they reduced the amount of paperwork and began the interviews with giving families an opportunity to "tell their stories." Interviews and focus groups ranged from 1-2 hours in length.

Data Analysis

Data analysis was continuous so that an emergent design could respond analytically to what was heard from subsequent interviews. Interviews were transcribed and content analyzed simultaneously as the issues and themes emerged from the family voices. Issues of credibility of data were addressed to enhance rigor of design. Credibility addresses the issues of integrity and congruence between constructed realities of the families and those realities represented by the research team and attributed to the families. The following three techniques were used.

Triangulation of Data

This involved bringing more than one source of data and more than one researcher's perspective to bear on understanding the issues and perspective of families. Focus group and individual interviews, questionnaire data, multiple researchers, expert panel, consumer advisory group, and video tapes were used to corroborate data. The perspectives of eight researchers/moderators and assistant researchers were involved in conducting interviews and analyzing data. The questionnaire data supported the interview findings.

Group Debriefings

During ongoing discussions and telephone conference calls, researchers discussed collective ideas and perceptions of data and emerging themes and issues. Working with several researchers, many in different time zones, created difficulties in regular communications, however the use of e-mail and meetings as several national conferences aided the ability of researchers to debrief. Interviews on the videotapes helped the researchers to see and know the families, thus enhancing data review and interpretation.

Member Checks

This is a recurring process of presenting information and interpretations to family members for discussion in a process that draws the families into checking the credibility of research and ultimately it's application. The consumer advisory group gave feedback and reflection on the findings of the study (e.g. does this summary reflect what you think was said? Do you have any additional comments?). Member checks resulted in clarifying several concepts into more family-centered perspectives.

Following established qualitative analysis procedures, we began by reading and rereading the transcripts to identify major themes or issues for families. Five levels of analysis were then performed:

1. A first researcher read transcripts. Major themes and issues in "synthesis statements" in the margins of transcripts (see below).
2. A second and third researcher read the transcripts and validated the original "synthesis statements." These researchers could also add issues or identify additional themes. If there were any points of disagreement, they were discussed until consensus was reached.
3. The "synthesis statements" were used to identify the major themes and issues for understanding AAC decision making from a cultural perspective. Some of the initial

issues that emerged were broad, for example: time issues, professional responsibilities, extended family involvement, support groups, transportation, and training issues.

4. In an ongoing process, interviews were conducted, reread, and compared to the initial themes and issues observed so that continuous feedback could divide, merge, or create new themes in a "constant comparative method." Issues were organized and integrated into three major themes that emerged.
5. Last, after reaching a point of saturation (no new themes or issues emerging), the themes and issues of AAC decision making were presented to the consumer advisory group for feedback.

Focus Group with Parents with AAC Devices

December 20, 1995

Mary Blake Huer, Ph.D., C.C.C., Moderator
California State University-Fullerton

Summary Background Information

Type of Group: Multicultural Focus Group (Huer)

Date Conducted: 12/20/95

Where Conducted: Classroom on California-State University-Fullerton campus

Number of Persons Present and Roles: 8 graduate students enrolled in Dr. Huer's U.S.D.E. funded training project designed to train S/LPs with special emphasis on cultural and Augmentative and alternative communication issues. Persons Present: Elizabeth Cates (Culture: Asian), Jeanine Arnaldo (Culture: Phillipines), Anissa Jones (Culture: African American), Su-Jen Shie (Culture: Chinese), Deborah Ziph (Culture: Puerto Rican), Elizabeth Makino (Culture: Euro), LaShawn Steadman (Culture: African American), Melissa Hicks (Culture: Euro).

Logistical Issues: No special circumstances

Modifications Required in Protocol: None. Protocol was followed as requested. Students complained about length of questionnaire; also noted that some items were confusing.

Synthesis Statements

1. Family Goals
   - Importance of facilitating family communication in home environment
   - Integrate child into family life

2. Family Expectations
   - Families have preconceived goals and high expectation
   - Some have unrealistic expectations
   - May be disappointed/angry
   - May see as panacea
   - Some will say no to technology

3. Stigma
   - African Americans can be double stigma
   - Call attention to disability
   - Asian Americans don't want to stand out
   - Euro Americans may experience less stigma
   - Latino-language tied to identity, culture, may reject if accent different

4. Voice Quality
   - African American females have lower frequency voice
   - Asian American voice quality not a concern
   - Voice represents personality

5. Collectivist Culture
   - Pacific Islands-collectivist culture would help support family to use and accept device
   - Latino-must work with entire extended family
   - Family system important to understand dynamics in accepting device
   - Asian-value placed on opinion of elders
   - African-device must fit with the communication style of the family
   - Latino families-not seen a time commitment-joy in community
   - African-initial stressor of newness
   - African-device must allow for several people talking at same time

6. Communication Style of family
   - African-device must fit communication style of family
   - Asian-children more quiet in family
   - African-children must be able to interact simultaneously with others in family

7. Decision-Making with Families
   - Latino-trust is critical for acceptance of device
   - African-involve elders in decisions
   - Pacific Island-mainly parents make decisions
   - Families view professionals as experts and don't participate
   - Asian-view professional as experts
   - Listen to families first-then joint decision making
   - Professional ask families what they want from device
   - Try different ways to elicit responses

8. Community Activities with Family
   - Pacific Islander-proud to take children out in public
   - Device should provide for culturally sensitive foods/ restaurants
   - Family will train people in community

- Asian-afraid to take children in public

9. Values and Beliefs about Culture
   - Professionals need to engage in reflective thinking about values and beliefs
   - Don't change belief system-understand others
   - Examples: Time in African view differently than in Euro-talking more important (DM also)
   - Asians get down to business small talk not important (DM also)

10. Family Perceptions of Symbols
    - Some not appropriate for certain cultures
    - Asian-more use to symbols in language
    - Don't allow for artistic expression
    - Color is stereotyping
    - Symbols reflect Euro culture
    - Don't reflect Pacific Island culture

Focus Group Transcript

I would like to thank everyone for coming tonight. The purpose of this group is to discuss AAC issues. In particular, AAC devices and how the devices will affect children and their families with disabilities.

For purposes of discussion they have defined AAC devices as voice output communication aides. So AAC devices are voice output are communication aides which require training to use effectively. That would include devices like the phonic ear devices and some of those other we have looked at. You are here because you have had experiences working with families or in the area of augmentative communication. in providing and thinking about AAC devices for children with disabilities. You also, I hope you will also have your own personal insights, feelings, experiences and so forth regarding the process of providing AAC devices that are important for persons who want prescribed devices to families. So that kinds the purpose of tonight.

My role as moderator is to help guide the discussion. I will present a series of questions for you to think about and comment on as a group. Again, I need to stress the focus of the discussion will be on the impact of AAC devices on families. That is the purpose of this project is to look at families and devices. Your thoughts and concerns will be used to develop training materials that will be used to help families, professionals, vendors and others who are involved in AAC decision making around the country. You know that by now that we have a camera and microphone to capture the discussion so that people can refer to it later. We have already collected the consent forms for each of you and demographic forms. We are also going to collect a little bit of tape for each of you introducing yourself- telling just a little bit about you interaction purposes for this Multicultural group discussion. So just a couple of sentences so we can have those introduction on tape. We are also going to use it to check out the equipment. Then I'm going to ask some initial questions and all participants will join in with responses and you may ask other questions of each other or me and kinda have a discussion. You can agree or disagree with any statement that is made. All opinions by group participants will be respected, again we will be recording you both video and audio. These camera sound personnel, their role is to make sure that we get good quality so that we can use it in the future. We have name tapes.

Some ground rules Some general ground rules that were shared with me. For focus groups- we would like to hear from everyone so that we hope that each of you will take turns making some comment. It's an open conversation. So you can ask question and respond to each other. There are no right or wrong answers. For this activity, you all are considered to be the expert. So whatever you say will carry a lot of weight. If you need to get up at any time, feel free to do so. Again, we would like to hear from everyone. When we speak to each other we will try to use names so that people know who is talking, it's very hard when we are transcribing an audiotape to know who said what and so that's why we'll try to use names so that they can kinda follow along- the graduate student who will be transcribing. There are no right or wrong answers. We are to respect each others confidentiality. These projects typically are very confidential, although it seems like it isn't at this point with the video and audio typically that's why your given a number and a letter of the alphabet. Things will be very confidential in terms of your comments and opinions and that will go through with the families and so forth.

Now, what I would like to do is also announce and would like you to signal right now. There is something called member checks. So if any of you would be willing to participate in a follow up contact by phone several months from now they would like to know. The purpose will be to do a member check. That is just to identify issues discussed by this group. So some one else will be calling and verifying that what in fact they heard was what you perceived what was said tonight. So if any of you would like to give you name and number you've done that on your consent form and you just might signal in your opening introduction. I would be happy to be called later.

Are there any questions?

Elizabeth: I'm Elizabeth Cate. I'm a second year graduate student. I just finished taking Dr. Huer's AAC class.

H: Okay great. Any experience with augmentative or the class or a particular client, or ?

EC: Not here yet

H: Okay

JA: My name is Jeanine Arnaldo. I'm a second year graduate student. I'm currently on Dr. Huer's AAC Cross-Cultures grant and my ethnic background is Philippine-American

AJ: My name is Anissa Jones. I'm also a grant trainee on Dr. Huer's AAC Across Cultures Grant. I also worked for a year and a half at the center for Ablide Rehabilitative Technology At Rancho. I have a lot of experience working with AAC.

SS: I'm Su-Jen Shie. I come from Taiwan. I'm a first year graduate student. I on Dr. Huer's grant too.

DZ: My name is Deborah Sipf and my first year as a graduate student and I'm on the grant also and it my first time with/exposure with any augmentative clients.

EM: I'm Elizabeth Makino and I'm on the grant also. I have no experience with AAC users. My mother worked in New Jersey with AA well, they weren't AAC users at the time because they didn't have any devices so it's interesting to hear her perspective.

LS: My name is LaShawn Steadmon. I'm a first year graduate student. This is my first experience with augmentative communication and Dr. Huer's class. We have done quite a few video observations so, I am familiar with Augmentative somewhat.

MH: My name is Melissa Hicks. I'm also on Dr. Huer's grant. I've done some observations in preschools in augmentative and with adult aphasic clients. This is my second year of graduate school.

H: Okay, now was the sound pretty good. Can you hear everyone? Okay great, They have submitted several questions and let me go through some of those not really in any order to lead the discussion. And see how you might respond. Again this is the group that is going to focus on Multicultural issues in these series of 20 or so focus groups. This will be the only group targeted to deal with Multicultural and because that the purpose of our training grant and because we have spent a lot of time talking about Multicultural issues we thought it would be interesting to share some of the experiences and discussion that we have had. So not only AAC but Multicultural as a part of AAC. What do you perceive, and I'm going to start with Anissa, then each of you can comment on this or spin off of it What do you perceive if someone were to ask you the goals or expectations to be for families and children who want AAC devices but have no received? So what do you think their goals or expectations would be for a family who wants a device but hasn't received it?

AJ: Is this for the Augmentative provider or for the goal of the family?

H: The goal of the family

AJ: Well the goal of the family primarily be out reach to try to find out any services, who in the community could assist them, and assist receiving the device also to develop ways in their home in which to make the person a part of the communication environment. Until the time in which they could receive some assistance I would think families would be geared towards that.

So mainly outreach, and looking for different services which could assist them.

H: Okay, Assist them to---

AJ: Obtain the device, or obtain an evaluation to see how they could include that family member into the communication circle in the family. I would think would be the primary goal.

H: Okay does anybody else have a different addition to that or?

DS: Are these the expectations prior to?

H: Yes, goals that families would have or expectations when they think we are going to get an AAC device. What do you think the families

DS: I think that they would have picture in their minds of maybe what the device should do whether or not they know what they are going to get, but maybe they think well this is going to solve this problem whenever it is that it is have a problem with or this may make my child vocalize more or they may have certain expectations what the device is.

H: So what it does? What it will do?

LS: I think they may have in the beginning fairly high expectations especially if they have not been exposed at all to the field of Augmentative and just like I said, just not really being exposed, they would have fairly high expectations of what the device might do.

AJ: I also think they have the expectation of what the device should output to them I need for my daughter to be able to say X. I need for my son to be able to say Y. They already have in their mind phrases or words or different communicative functions that they want their child to be able to say. They are just looking for a device that will meet the expectation that they have in their mind. So I think that is something for every clinician to keep in mind that a family already has in mind that my daughter or my son can not communicate. He or she needs a device that will say ----They can offer so much information to that initial vocabulary that initial beginning. That's their expectations- we're going to get this device so you can tell your mother ------.

EC: I think that some families might have some unrealistic expectations to. Like, this device is going to be a miracle all of the sudden my child is will be able to be like every other child. I think that is something we have to deal with to getting their expectations to a level that is realistic

H: That's interesting because another question is asked is - Do you think after they receive a device that their expectations change or their goals change?

DS: They might be disappointed at first, they may be angry because it may not be doing what they want it to do. That's why do the questionnaire it was kinda hard to answer that question and that when the support should kick in probably the most. When they are so disappointed and the device is not providing all this miracle that they had in the back of their mind even though they might of been provided with training and all of these things they may not have heard what was being said. They may be angry and not want to use it.

LS: And also since we are so technologically advanced in our society they may look at the device as - this is a computerized device it should be able to do everything and not really take in the holistic nature of communication and the training that is going to have to go into not just the technological device of the system that the multi-modal effects of communication and the training.

H: um, huh

AJ: I think one issues we need to talk about is how different cultural families will perceive getting augmentative. Because I was thinking in my own culture African Americans it might be I'm glad that My child has a way to talk but also how is the world going to perceive my child being an African American and also handicap. That's like two negatives when you deal with a big society that doesn't look very positively upon African American. So it's like I'm glad or I want this device to give us this assistance however how is the community how are other going to perceive my child with this device? So we also have to be very cautious about how other cultures perceive technology. Every culture is not embracing technology that could be based upon religious beliefs, different cultural values belief systems. We have to be very careful to just say look at what we can do for you. You have to be very cognitive that some families are going to say thank you but no thanks.

SS: Yeah, I think that's for Chinese families. They have do with the resistance to technology. Because AAC devices will bring stigma for most of the Chinese family.

H: Interesting, Can you expand a little bit more on the nature of that stigma or how they may perceive that?

SS: Because I believe that most of the Chinese are afraid losing things. Afraid of how people look us look at me . so they don't want to do anything that is different from others. So that the AAC device makes you stand out and makes you different and that's a stigma. So they have to deal with it- a resistance to AAC device first.

H: In Euro American cultures, some parents perceive the presence of the device as very positive. So it's interesting to look across cultures. If some cultures perceive it as a stigma and others perceive it as more positive. Any other thoughts- You mentioned something- I'm trying to remember the phrase you used to expand on

H: So the actual quality of those voices is

AJ: right, exactly

H: Jeanine- How about the Latino culture? Do you think, what you their perception of the voices be?

JA: I don't think they would- From my experience I don't think it would be that much of a concern as much as to them (points to AJ & DS). When it comes to devices, in the Philippines they don't really have they not really technologically up there so there not really aware of what's out there. I think they would be more concerned about I think they would like it. They would like the idea. It's a great idea for them. But I think they would be afraid of it also because they are not sure quite how to go about using them or I think they would be intimidated by them.

H: So They would be excited by the presence of technology, Yeah, but a little bit

JA: Intimidated ,

H: maybe something would break or they are not comfortable or but not the quality of the voices.

JA I don't think that would be their focus. They don't really pay much attention to that. That's not like a important

H: So Jen what about the quality of the voices?

JA: I don't think it's as much of a concern.

H: So not as much of a concern. So cultural differences seen just to actual quality. Melissa what would- you just spent some time in an Asian community at your advanced placement. Do you have any sense of Euro American perception of quality verses.

MH: I don't know. I worked with an older population. I don't think they would be receptive to the technology.

H: But not because of the quality of the voice?

MH: Not because of the quality, but because of the technology and they kinda shelter the elderly. They kinda keep them in their home they don't get out much. They kinda take care of them.

DS: In the Latino culture language is so tied with identity. It's just a part of who you are and even if you speak English fluently. If you have an accent or if most people around you have an accent and here is this voice who is supposed to represent who you are comes out in perfect English it's not just who you are. Language represents a part of what you want to give to the world and if you have grown up with people who speak Spanish or English with an accent that voice will not represent who you are or who you what people to see you as. So even if not the child or not the AAC user the family most likely will reject if there are first or second generation who are very in touch with speaking Spanish. they will most likely not want that voice coming out of their child.

H: So that voice being--------

DS: That voice being an English speaking Euro American voice

H: Okay

MH: But there are digitized

AJ: Even the digitized voice output. They don't have it's in the literature that African American females typically have a lower fundamental frequency. And if you look at the voice output selections for devices none of those devices are really suitable for an African American female. So even if you put the lingo in there like the guy (one of the vendors who showed us a system) He put what's up in this machine and when you go across the device even with whispering Betty "What's up" that just doesn't sound African American. So again, with language represents who you are in your community, your gonna been seen as an outsider because you have a voice output that not representative of your culture or how you are or if you select a mans voice that's not very appropriate for a female.

EM: Well I don't think those voices represent any culture. I think they are just cultureless.

AJ: Yeah, and they typically are not appropriate for African Americans or someone else who is coming outside the Euro perspective. I think either more so a where language or the oral communication is so highly looked upon. That is gonna be even more of a stigma, because there is such a high emphasis on oral communication in those cultures.

DS: Especially in the African American culture in the Latino culture oral communication is deemed at such high levels . That verbal communication I mean if you can speak well if your a good speaker, Puerto Rican if you can tell jokes and entertain your the most popular person. Okay, and if your a good oratorical performer or whatever you want to call it. That is just one of the highest qualities to have in the African American culture.

AJ: That's how history is passed down, that how folklores are passed down it's so such a high emphasis placed upon that.

EM: Kinda like my in-laws house. My husband is Japanese and there was the grandfather and at a family gathering he sat by himself in the living room and everybody else was talking to each other. He was just off on his own.

MH: A lot of the patients sit at home all day watch TV or take care of the grandchildren. But I have talked to the interpreter at the hospital and he says that child would be a lot more receptive especially growing up in the US.

H: So if I were trying to summarize what's being said with regard to technology there's positive and negative views of just the presence of something that is technological that may be culturally bound. There's differences in perception of culture based on the quality of the actual voice that comes out of it the device. Another question is- if you look at the family unit the family as a unit and we know that we have had discussions about nuclear family verses extended family and that's cultural too. Some of you might share some of that in this discussion. But the question is could or does and AAC device positively impact the family unit? However we define that and or would the presence negatively impact the family unit? Would anyone like to speak to that the presence of it?

EM: I think that it would depending upon the family and the culture it would positively impact in that it would bring that user into more communication into the family and make them more present in the family. And that will have negative results to maybe when personalities clash or whatever

H: In terms of participation, Any other

JA: I can only speak for Filipino I think it would be positive thing. The whole family will come together and they would look at it and say wow this is great! Everybody would try and do whatever than can to help make it easier for the child/adult or anything. Cause that's just how the family structures Everyone sticks together, everyone takes care of one another. Just like Melissa says with grandparents- we take our grandparents in, they live with us for how ever long they need to, if they needed anything we get it for them. Everyone takes care of one another. So, I think a device would be looked positively on if it could help them. If they could benefit

H: Any negative impact?

DS: I think for somebody who is again first or second generation Latino. It would take a lot of trust for them to embrace a device a device like this. I think Dr. Soto mentioned this when she was around. A lot of listening to things that how nothing to do with the device, a lot of listening to -checking- making sure the person really cares about the child, and trusting that person in order for this family to embrace the device And then depending on- the whole family may not be involved in this so it may actually pull some people apart. If the father is not that involved with it, or the uncles or whom ever lives in the family and then a couple of people are involved and trained with it and their the ones who primarily may communicate with it. I think in an extended

Latino family it would tape a lot of family counseling and a lot of involvement with the entire extended family for everybody to work together. As if I looked at a Euro American family with just 2 parents and a child, it would be a totally different dynamic system than with the Latino family.

EC: One negative thing I can think of- if your living like a lot of families do where it just a mother, a father and maybe a couple of kids at home and the grandparents live across the country So you don't have a lot of support is just the stress of taking care of a child with special needs and then in addition having to learn this new system of communication. I just think it might place a lot of stress on the family, especially if it was a single mom or something like that. It would just take a lot of outside support.

EM: The sibling might get jealous.

Group agreement

H: I remember when I gave a device to a child in a school once. and other children had a communication board and this particular child had a device and so the teachers almost left her alone because the device could speak so they didn't need to sit near her anymore to watch what she was pointing to. I remember that the other children in the class felt a little bit sad because they didn't have a device but I remember saying but you have adults. Because in order to communicate we have to be with you and she can now be alone more because her device can call, and she can store messages. It was kinda interesting that dynamic. I'll never forget seeing that effect, and I hadn't expected it until the device was set up and delivered and she was kinda left alone because now she could be more independent. So it was kinda interesting.

EM: Does that issues come up when they move into adolescence? Where they don't want to be so dependent on the partner? They want more independence.

H: I haven't had a lot of experience with adolescence users. I've had the college age. I'm not sure, I suppose it would depend on how long they have had the device or when the device was introduced. So I haven't really had any personal experience.

AJ: I would say to the clinician to be very careful and judge or try to assess the family unit very differently. Because I have an older cousin Walter who has Cerebral Palsy and I can remember distinctively the day that he got his first power wheelchair. I can remember every cousin, every aunt we all went over to may aunts' house when Walter got his wheelchair. We all wanted to see him ride I his wheelchair. That was our sole purpose for going over there- was to see Walter in his wheelchair. So I think that would be the same thing if someone in my family got an augmentative device. We would all go over and want to talk to this person. Once my grandmother saw the wheelchair and saw Walter in the wheelchair and she was impressed with it, then we called everybody. and everybody came to see Walter in his wheelchair and it was a big thing with the cake and the balloons.

H: What happened then?

AJ: Walter just went around in his wheelchair. Then we all went Oh Walter. Then we started playing games with him because he move out of the house without someone carrying him and we went on from there. I can remember everything he got when he moved from the wheelchair and got his braces. That was another big thing. We all went to see Walter walk with his PT with his Braces. That was a big step in our family because he had Cerebral Palsy we all gravitated towards him and it was seen as look at what we are doing now, not like Walter has braces and You know we don't have anything. It was like no now we can walk, now we don't need a wheelchair. So every family is going to accept it and deal with it in a different way and I would say get to know all the family members, get to know the key player and see/feel out how they are going to accept it or deal with it because every family is going to react totally different. It just all depends on the dynamics and how close knit who is considered a family member. If that person is a single parent or not. The dynamics play so differently so

H: So one of the questions Dr. Parette was interested in was would the devices affect the roles family members must assume and from the story about Walter that's an example of changing roles in families.

AJ: Cause we all became members of Walters' team. I can remember when he was first you know, doing Walters first everything was a big celebration for us because he was very involved as a child. So every family is gonna to take it differently and every family is gonna to deal with it differently. But the person for us was my grandmother cause she is very resistant to a lot of things. but she also the grandmother which we all hold a great deal of respect for so once she approves of it. Well I can see how that would work for him, or if she doesn't feel comfortable with the person. No he shouldn't go see that therapist, I something about that spirit didn't click with me and we won't accept it. And that's give and take with good judgment and everything, but every family unit is totally different. My family operates probable totally different than everybody family up here because there's so many people involved in the discussion. I remember telling you one time oh well my grandmother thought that was a good idea so yeah. (laughs) You were thinking your grandmother, but that a big part of how we do things, it would seem more to me if my aunts or uncles would approve of something then to me that would be like well okay.

SS: That is true for Chinese family. The seniors like grandparents and relatives uncles, aunts their opinions are usually valued very much.

H: So the presence of an AAC device would affect roles that family member play and that not very defined in our literature, certainly at all in terms of the roles. So

AJ: Who's the decision maker? Cause a lot of times they are looking at the mother and father and not understanding that the parent is going to go back and ask their mothers or fathers what do you think about this and look at this and they said this device could do this and what do you think? And then their going to call another sibling I don't about anybody else's family but we play the phone tree thing. Yeah TiRose what do you think about that? Well no call it to Aunty Darlene and we bounce it around and then when they make a discussion. Well I like this one the best, so there are a lot of people in the background who are making this discussion when that parent is going to be the person who will tell you the decision.

H: How about in contrast in Euro American culture family roles and decision makers? I know some of us have talked about studying decision makers. What do you think in the Euro American family? Let's say two parents and one child or one parent and a child.

EC: I think a lot of times the mother is the main caregivers a lot of times and if the child is gaining more independence the mothers' role is gonna obviously change as her child becomes more independent she gonna have to learn to back off and let the child be more independent So that's one way her role could change.

H: There's also a changing role in the literature, where when the partners have to help in the expression. If a person doesn't speak or communicate then as a communication partner you don't have to do very much. But as a person begins to be able to communicate, then the listener has a very active role that they didn't have until that point and that's uncomfortable sometimes because you want to facilitate it but it's not the typical communication dyad that we have so that's an interesting change in role. How about relationships with family members? Do you think the presence of an AAC device would impact on relationships that family members have?

EC: With each other or with the AAC user?

H: Probably you could answer it in either of those contexts?

EM: I think of the voice as representing the personality and it would be really hard to listen to the voice and keep in mind that the person's personality that your really communicating with it is almost like the voice would be a barrier to reaching that.

H: So it goes back to the earlier discussion that we had.

DS: I would think that once the voice is accepted. If it's accepted, that it's almost like seeing that person on a different light. If they didn't have any communication before, it like maybe parents talk to each other before to find out something about the child and now the person can actually say things and or let his/her need known. Now they maybe have a different look at this child as a whole person with communication.

H: And time demands. Do you think that AAC devices introduced into a family change or impact time demands within that family?

AJ: I would have to say yes and I think that with any child who has a particular specialty. That time demand required for that child is gonna be more than someone who does not require additional assistance. and it's just you give the child that time but it would not be looked upon as negatively it's just like this is what you need so we're going to give you whatever it is you need. So it a different amount of time but it's not perceived as different.

H: What about in other do you think time demands by device would be culturally bound? Would it be, Melissa your nodding you head?

MH: Yeah, cause I think that it might be resented all the time that's needed to put in this device in helping this child. The husband will resent it and the wife spending all of this time with the children will resent not getting equal time.

H: So if...

MH: in an Euro American

H: we are looking at decision making...

MH: time, we never have enough time

H: yeah, that's interesting, Any other perceptions?

DS: To me it would in the extended Latino family I think that it depends the way in which it's presented. If each person had role and the person was getting something back or doing that because the person would be able to speak. It would be more of a joy to do it. Oh I'm going to do this because and you get to do it Pedro you get to do it with your brother because you will be, your gonna get to play with him. Grandma gonna do it because she's gonna be able to talk to her grandson and everybody does it because it gonna make this person talk. So in time also it not seem like okay one hour, it's just well this is the activity. It would be more of vague type of situational thing where maybe on Sunday mornings after church grandma spends time with him working on certain things of the device. I see it more loosely rather than okay this is the training that it takes and each person is responsible for this. I see it more of a interactional type of role where each family member is feeling like they are putting something into what's going to come out of it.

H: How about organization of the home environment if we kinds more broadly would the presence of an AAC device impact the way the household organized or if you looked at a very structured family verses ......

AJ: moving furniture or like that question

EM: why would it be any different than just having in the household in the first place I don't see how it would make a difference.

H: How about stress?

EM: With a device? Assuming that

H: Would it affect levels of stress currently experienced in that family?

EM: Assuming that the user in the family living in the home already

AJ: I think any new thing may present an avenue for stress, especially if your going to wonder well is my child going to be able to use it at school is he going to be able to use it may think as a parent. He's at school right now, is he using it? Initially, is he using is properly in the class, can they understand it, did the teacher pick up on it? You have those type of worries or concerns which initially can cause stress but I think with the proper training and the correct intervention from other professional that those areas won't become stressful but I think that is one to see to how well everybody else is going to accept the device and be able to interact with it.

EM: You know your right, cause it's like when my kids got retainers, are they wearing it, did they lose it at school, did they throw with their lunch. Things like that, I guess it would

MH: What about just the technology, I mean because I hear about all these devices in drawers I mean it seems like the stress of what do you do with it? How do you train the child? or

LS: Initially just dealing with the rate of communication would be stressful. We have to wait for this child or this person to respond. That takes getting used to. Like Anissa said it all goes back to the training. How much time is the professional going to put into the family in training them about these issues.

EC: I think you could reduce stress too because If your playing twenty question with every thing in the child's life trying to figure out what they want and then all of the sudden the child is able to initiate some of his needs and tell you what he needs that would relieve a lot of stress. I think in that way

AJ: I think it's important tot mention that when your doing that training take into considerations cultural conversation or communication styles and patterns. Twenty question does not work with an African American. What do you want I would like...... That's just not how African Americans typically communicate at home. There are usually several people talking carrying on a conversation and your conversation is just as valid like if Su-Jen and I were talking and Deborah and Jenine that's perfectly fine. So we need to teach the AAC device user how to effectively communicate in their environment, if in therapy the AAC user if going I'm fine, How are you Su-Jen? Su- Jen responds to me that's not to transfer when they get at home. They are gonna be lost and then were gonna see that passiveness again. So, that will create stress. They are doing it in therapy, how come they're not doing it at home? What's the missing link? The missing link is that therapy is not reflexive of what's going on at home it doesn't imitate what goes on in their environment. So that's very important for the device to be successful and effective in the persons communicative environment.

DS: Also in the Latino culture it's almost, it just has a little different twist, it just highly cooperative type of environment where children are not expected to prove themselves. They are not put into a position. I always felt very stressed out when I had to play sports because your never put into that position. It's like only when you play sports you never put into a position where you would have to be competitive like that we all do things together, we all learn to cook together, your cooking with like with 20 people in the kitchen. It not an organized- you do this- no we're all doing it together. You see kids all over the place and their all learning. And that's how you learn. by watching and by doing and the same thing when you communicate, everybody is talking at the same time and you may not think that your listening to what's happening but your are. You may be talking on top of the other person, but that perfectly fine. It's not about oh I'll take my turn, okay I'll wait for you to finish. NO you learn to jump in

AJ: Yeah, and interruptions aren't seen as a bad thing. It's like oh but I had this yeah did you . It's not seen as a bad thing so communication styles, and learning styles all this needs to be taken into consideration during that initial training or else when they get into their home environment that's where your going to see the breakdown with the family because they haven't learned how to effectively communicate with the family

DS: and I think that part of the rejection goes back to that initial they keep going back to acceptance. And they didn't accept that person initialing there 's no way they will even if it shown that this device can do all of these wonderful things. There is no way that a Latino mother would use that with her child because this person was not trustworthy. Even if the person was but for some reason this person.. trust is very important and at that initial consultation or whatever if that person came across and patronizing and insulting or maybe in a way that the mother couldn't relate that the device will never be used.

H: Su-Jen, Am I perceiving that you have some......

SS: Yeah, Yeah, I was thinking of a Chinese family, the interaction will be completely different. Like when children are with their parents, grandparents, or other relatives who are older than the children. Usually the children are not encouraged to talk/communicate. They listen more, so that for an AAC user he/she would just wait.

MH: It seems like AAC is like another culture though. I don't see how you can have talking at the same time because you have to program it in.

DS: right

You know it's not like you can just

DS: I'm sure you can

AJ: I've seen it happen

DS: I'm sure you could do it

MH: Oh really

AJ: One of African American male at Rancho received a device and one thing that was encouraged his grandmother, mother and an aunt to the evaluation and they were talking what do you think about this symbol? I don't like that one? He would say yeah. Just like that and then I don't like this one. And the grandma would pass it. That doesn't look right to me and he should say no. You know so you can take your turn in that dynamic just the same as if you had if you, it works just like a voice. Communication is communication. It has to be taught that way initially or else the other family member are not going to reject it. If you sit back and you wait you'll be waiting because

MH: I can see that, but how can you talk at the same time? I mean because it has to be planned. I mean your always having to plan- program it in before you say it.

AJ: Just like you program your speech. I mean we can't think about AAC as like a robot. This person is going to say well Deborah is talking about something like that. But that person is going to program it into their device and speak it just the same. Now the rate may be slower.

universal agreement

LS: Yeah that's what she's referring to

AJ: oh, okay

MH: That's what I'm saying how can you do it at the same time?

EM: This is one part of the conversation going this speed and other be lagging behind

MH: well you kinda have to change you cultures to I mean within the home

DS: (laughs) I don't think so

MH: Things like- I mean you have to change your interaction somewhere

AJ: To some degree-- the rate of it

MH: or slow it down

DS: I think that if there was some kind of family interaction and this person wanted to interact. I think his voice coming from a device first of all will call attention to.....Their conversation will be all the way here and he's answering to something over there and they'll just go back and I don't think it's going to be a big problem. I think, I would say okay your talking about that okay and then they'll start it again and then they'll go again and then they'll caught up with him. I don't think it's gonna be a big

MH: I'm just courageous

(laugh)

H: Clearly with the differences in this group, which is why it's been a fun semester. There are differences in communication style and in order to work with families appropriately as professionals as practitioners we have to be real sensitive to all these differences that you expressing, because we all have our own experiences and our own culture and it's got documented that persons with disabilities are a culture and persons with AAC types of disabilities are also a sub-culture of this larger group of disabilities. And in addition then they bring their own culture, whatever their ethnicity and experiences have been. Some it's interesting all of the differences that have been expressed kinds encapsulate what professional need to become familiar with and families need to understand if you have two different ethnic groups interacting in the clinical processing makes it really interesting which is kinda what our grant is about. If we take this further, and know look at the family however we define that and the AAC user with a device and go out into the community, like restaurants, or recreational activities or social activities do you thing there are or is an impact because of the AAC device so that family as it enter the community so we get a larger circle of participation. Anyone want to comment on how the device may impact that circle or change or effect throw think go beyond families go into the community and you can speak to a particular culture or a more heterogeneous group in terms of the community. Jenine you have

JA: I'm trying to figure out exactly what your asking.

H: So think of recreational activities, these are some- eating at restaurants, social activities. When the family takes their child does the AAC device impact the families ability to take their child into these community type of activities?

JA: I guess for Filipinos I think they would be proud. They would feel like my child has this and it's wouldn't stop them from going out it wouldn't stop them from doing anything they would be proud of it and show

H: So they would use it freely,

JA: Oh yeah, were as I guess so families would keep it hidden. Filipinos would take it out. They wouldn't keep their child at home they would take their child to parties. I went to a party a couple of months ago and there was a girl there who was not AAC but she was blind, but they had recently got her a seeing eye dog took her to the party she was just like everyone one was around her and it was just great. I think it helped her more because I remember seeing her a parties before and she would sit in a corner and no one would pay attention to her but, this time she had her dog everyone was asking questions, people were playing with the dog. She had a crowd around her

H: Elizabeth, what do you

EC: I don't know about with a child but with somebody who was an adolescent or young adult it would give them more access to a community they could make their own doctor's appointment, or order for themselves in a restaurant. So it goes back to independence getting more independence and more access to the things that are available.

H: Other comments about AAC devices and impact on community?

DS: The only problem that I see is that a lot, of couple, or the two or three devices that I seen really for the community really don't provide culturally sensitive restaurant or foods that people in those communities would be ordering. I think that as far as bringing the person out into the community as long as the family accepts the device I think the community will be watching their interaction and will follow. It's not a big deal once they're out, I think the interaction within the family members will be very important and it's just as long as the family accepts it I think it will be like a novelty and it will be Oh, he can talk now, it's just a matter of the family to training whoever comes in contact with the person. So that yes you can ask him he can order. he can tell you what he wants that type of thing.

AJ: I think clinicians need to also be aware that once you impact one family you can have the potential to impact many in the same neighborhood. So many neighbors of our will call our house. You guys got Walter a wheelchair and now such and such a person needs a wheelchair. Who did you go to and what was that person like? and those types of things so it's not once you the family accepts the device it's very true the community will and will look to you to say who did you go to and how was that person and what did you agree yeah did she like that person, we're gonna go try that out. So it's very important that once the family accepts it that the community is no problem, but you know just for the clinician to know that several other families are watching to see how that family is going to react to it and accept it.

H: Su-Jen Do you think the Asian community shares that experience are their differences/ similarities?

SS: I'm not sure but I think it's very possible that a family will be afraid of taking a child with a AAC device into public. It's possible, but I also think it depends on the parents education background.

H: Could you expand if you can a little bit of what they would be afraid of, where the fear, what would be the source of that?

SS: Just as I say before, the stigma

H: So there would be a discomfort?

SS: Right, and then they you know other people would just look at your child so it make you uncomfortable.

H: So calling attention

SS: Attention right, right, but people with higher education I think that they would take it more positively. They would look at the device AAC system
has to be.

H: Let's move to a different type of question now. if the if we look at family members roles. Assume that we're making decisions now about purchasing devices or selection in fitting devices. What do you see? How would you describe the role of family members in the decision making process? From your own perspective?

AJ: Very Important, if your looking at an African American family to consider the elder members of the family. I would invite them to the assessment. I would try to educate them as much as I educated the family because it, we're a unit we're one and the elders their opinion matters so much so the unit will accept what the elder says. We don't really see it as this is my family you know my husband, myself and my children we're just all seen as one very connected, very and that device is gonna be shared among all of us, We're all gonna have to learn how to work with it because we're all that one person really.

H: Jeanine, would that be similar

JA: Yeah, but I think primary the parent, both the parents. I mean you would get support from everyone in the family but the main people that would make the decision would be at least in my generation. I don't know how it is way back when. It would be mainly the parents making the decision.

DS: I was curious if lesions' experience would be the same?

LS: They would be pretty similar.

H: Do you think there are cultures where the families wouldn't be involved or included in the decision making? I suppose on a continuum you could have a role very involved and not involved. Can you think of

EC: I think that I have worked with I think that clinicians let a lot of families know that their opinions are valid because a lot of times they sit back and think that your the expert your gonna make all the right decisions and they don't give you as much input as they probably should. So I think we really have to emphasis to family member that their opinions are really important in the decisions that we make regarding AAC devices.

H: In an Asian community would the parents or the family be actively involved in decision making.

SS: I think so, they would be

JA: They would make the ultimate decision but like she said they would totally respect what the clinician says whatever they say that's what they believe because that's what your an expert in. They don't know anything about Augmentative whatever for example If I needed a device, and a speech language pathologist said oh this device would be good for your child no matter what, even if it was or wasn't because that Speech Language Pathologist said that was it. They would do whatever it took to get that device no matter what they would just believe in the professional.

H: Do you think that should be changed? Do you think that's

EC: I think we better gain a lot more knowledge if we're gonna have that kind of power.

H: We meaning professionals or we meaning families?

EC: Professionals and Families

DS: Both, Well I thinks as professionals we need to be knowledgeable about the way be are being perceived.

Right (group agreement)

DS: Um, one thin that I'm hearing and I have to make sure that I make clear to when I Latino families, what Anissa said was very important to as far as each family is very different. We're talking about people who are different generations. People who have different levels of acculturation. The more acculturated the more your going to accept what a professional says without questioning sometimes. Even the least acculturated the least you will say it. Um, and it usually depends on the individual family. um I think as professionals we need to know how that person might be perceiving us and me being letting the person speak more. At times we go there and we present Oh this is what I think, What do you think? So of course they're not going to say much because we already stated our professional opinion. Their opinion, they don't see their opinion as valid as a professional maybe or maybe they do if they are assertive you know no matter what their background. but I think we make a big mistake when we go in there and say this is what saw this is what I did, this is my opinion. What do you think, I think we should let them talk first and give us all everything and then let them know that this is a joint decision and it not up to us and we can make our opinion.

EC: But sometimes, sometimes when just working not with AAC clients but with speech and language when you say what are your goals for therapy a lot of times they have no idea.

DS: Because, what is goals?

EC: right

DS: you know Your asking them about something ...

EC: But what do you want to get out this therapy/ training session? A lot of times they don't really have any idea of what they really want. So

DS: I think you have to put it into a framework though. I mean kinda point out the problems and I mean I think you have to walk them through it. Like in therapy for example I usually ask in my initial I say okay " what do you think Johnny is having problems with? and then they'll say and I'll write it down. okay and then I kinda walk them through it kinda asking them, kinds spoon feeding the answers out of them but If I were to ask them what should I start with. I don't think that they could tell me that. I think that we need to learn to kinda take it step by step. It's easier to do it. you know just not ask them. It's easier to just go in there and do our jobs. and then it's done rather than sit down and listen to what their concerns are. I mean is sounds mean but you know you go do an evaluation, you write your goals and then you talk to the parent.

EC: Right

AJ: That's the way it's done. And also consider the person, the AAC user as a team member. In this fall semester I had an adult client who was an AAC user from a traumatic brain injury and the first thing he said to me on his board was that I want to talk with you and not to you. That was the very first thing he wanted to be included in the- you know causal conversation that I have before therapy and after therapy. He not only wanted to learn the symbols on his device and how to put symbols together to say phrases he wanted to be able to talk with others. So I think a lot of times we are asking - what do you want, you know the family, what do you want out of therapy. Turn that situation around put the spotlight on who you want to help and say what do you want out of therapy. Make him tell you, they know exactly what they want to say and do with that- in his particular case a board but even a device they will know what they would like to be able to do cause their the ones whose been locked in.

H: Other, How about your values and beliefs as clinicians. Do you think those impact the process? Are there differences in because of you personal beliefs and values in decision making?

EM: I can see just from doing the exam for this class that I really value academic achievement and if I think that the client has any chance of learning orthography or the capability of reading and writing I would wanta pursue that and that might not be appropriate for all clients and all families that I would probably might push for more achievement than maybe was appropriate.

H: Do you think maybe you could change your own belief or value system, modify it as a clinician?

EM: I probably could I don't know if you would make me happy.

Group laughs

H: I think that when we look at Multicultural issues that will impact our practices in AAC and in this case impact our practices with families. We have to look at ourselves and do some self reflection. So I think that's an important question to reflect upon for each of you your own values and beliefs impact that decision making process.

AJ: I know for me I'm real interactive person and when looking at the client I kept thinking to myself how could I make that person interact with their communicative environment. That the route of my report. You know I want this person to use this device in their communicative environment.. To me therapy is like the ideal situation. If you could only talk to one person for an hour what would you say or do. But I'm so interested in what the person can do in real life that that's were all my goals and my focus was at. what are you going to be able to do when you leave me? Me is ideal, but when you go out there within your normal environment and but are you going to be able to do? And maybe I need to strike more of a balance and look at you know we need to have a balance as a whole and I'm always looking giving the benefit of the doubt. Let's try something different I remember doing group therapy with other clinicians this semester. They would strictly go by the lesson plan and when that lesson plan didn't work oh, well it didn't work. I was the one- let's pull another trick out of the bag let's try it this way. Because I know as a person of color sometimes a person will not know how to get the information out me but if they would've tried it a different way I would have told them the answer to the question they wanted to know. But because they don't know how to ask me I didn't give that information because I assumed something different. So I always take that same assumption when I do therapy maybe I'm not asking or maybe I'm not doing this task in a way that will draw the answer or communication out of you. So let me try it a different way and I think that's something as clinicians or as incoming clinicians that we always need to have. Let's try the same thing a couple of ways. I think that will help us or help me meet, reach more communities in different cultures. That willingness to try and try again.

LS: To expand upon that, if I were to have a client of another culture I would not necessarily change my beliefs and value systems I would be more prone to look into their beliefs and value systems because I want my therapy to be affective for that client so if for example, just from this discussion tonight if I were to have an Asian client for example I'd want to learn more about that client's values and beliefs again not necessarily changing my beliefs that who do we want to be more effective for.

DS: And even going on that when your looking into that client's beliefs and values then you may have to change your discourse style with that person, whether your more direct, indirect whether they way you present yourself to that client. Your just changing your style for that particular client so that you can communicate with them and by accepting their values and beliefs your almost your validating yourself to that person because their values are what's important. Not your opinion,

um, huh

DS: Their values are what your not trying to violate.

um, huh

AJ: And I think that therapy setting in itself is set up in a manner where you really have adjust. I know for African Americans time is perceived very differently than the Euro American. Time is perceived, time spent talking is perceived much more valuable than time spent doing something else. The experience of communicating and sharing time with others is perceived at a greater value. So for African Americans clients you know maybe to sit down the first five minutes you know to get to share a little bit before you go straight into the task because if you just, I learned this because I'm a task master. I just say you came to therapy let's work and you have to back away from that. You have to say how was your day? How was the trip over here? Tell a joke, my client who used the AAC device wanted to tell jokes and communicate for a little while before when went to the task. So you have to be the cameleon, you have to be able to change and move and dance to the dance of your client to the beat of your client in order to be effective ??or your gonna miss it.

LS: I think that's your professional responsibility.

yeah

SS: I would say that way for Asian client just Chinese just cut the crap and this done this business done.

Group laugh

H: So very different

SS: Very different, don't socialize and you know with do not ask how are you? you know questions like that. They're not used to that. Just get the business done.

H: It would be interesting if you had to two clients back to back, Group laughs

you would really have to shift than

H: Last couple of questions if to add anything else that we haven't talked about and there is another part of a question that speaks to anything about to devices that parents may not know and the way that this focus group has been compiled is focusing on the phrase AAC devices but as you know in this class we've kinda broken it up. There are a lot of components of AAC devices. AAC devices aren't generic and there are a lot of issues, we've talked a little bit about some of them the voice, the quality of the voice, Melissa mentioned a little bit about the speed but there are a lot of things we've looked at in regard to symbols, the actual appearance, we talked about color, there're a lot of issues with regard to those devices that parents may not be aware of and that Dr. Parette may not be familiar with in regard to cultural issues and those components of the device. I would like to end tonight with the anything else that you might want to contribute in terms of your own thoughts and review of materials from this semester some of the papers or impressions you've had or perceptions with regard to symbols, symbol sets maybe approaches to decision making, evaluation, selection and fit. Anything else with regard with devices. I don't want to put words in your mouths. But that may be important information to be shared that would impact families and their selection, their initial entry into the world of do I want one of those devices and then after receipt of it that. That's kinda a vague and open ended question. Melissa do you want to start to comment on anything else about device components of AAC devices that may impact?

MH: Well some of the symbols are not appropriate for cultures

H: okay

MH: Like the foods, colors, expressions, even the look of them also in the translations I just wonder how like with the Asian language how they get the tonal stuff, you know tones and pitches

H: Su-Jen wrote something about that in the paper I don't know if you can remember some of your comments or thoughts Group Laughs But I think it was interesting.

SS: I don't remember

H: You talked about blitz and Chinese characters

SS: oh yeah

H: and the way

SS: Oh yeah, I said that the way blitz symbol combines similar to Chinese character combine.

H: What would you thing of a person in your culture beyond the voice , let's say that we talked about the voice quality but just look at the symbols the overlays what would be initial impressions? Do you think?

SS: I think that for a Chinese it would be I guess it would be easy to accept with symbols for instance, because we are used to the graphs and the it's not a spelling language so I think it would be easy for them to accept it. To accept the symbols and also the logical to combine the components together.

H: How about the ordering? I think we usually go left to right.

SS: For older Chinese it better to go from right to left or top to bottom, But for younger people, like me you can go either way it doesn't make any difference.

H: Well that interesting Any other Liz

EM: I'm mainly offended by the ascetic value of the symbols, and I don't think they don't allow for any Artistic expression. They take language out of the realm of artistry and uh

H: Can you think of a specific example?

H: Well I guess the pic symbols I guess there're the ones

H: pic syms

EM That look like there're from the 1950's and they just didn't seem to have and personality to them. They're so generic that I can't imagine using them and feeling that they were expressive of me or of the people in my family. You would have to take it and translate it into just a take the words and translate and try to fit the personality to the words that are coming out for the symbols being used rather than having those the be an expression of the person.

AJ: I think we also need to be very careful when we do use color. I found it very offensive when we had a demonstration of a board that used color and they used the color black for the symbol help and there was the face a black person in the front with the motion of a black person moving behind them and that to me was very stereotypical as if African Americans are the only ones that perpetrate violence or that's the only need for help or they used the color black for action. That's one of the stereotypes that African Americans are very active and moving people and you know.

I thought I don't want that I wouldn't want that as soon as I saw the color. I don't care what it could do. So we have to be very careful.

H: Jenine?

JA: I think that the symbols are very Euro American. I don't see if I were to think of my generation would be okay with it, But if I were to think of an uncle or an aunt or anything I don't thing they would be able to use it. They just don't represent our culture, they don't represent anything there're used to I mean if they were to come from the Philippines to the United States a lot of those symbols would not represent anything I mean the food alone. Didn't represent any thing that they are would be used to they don't have hamburgers and spaghetti and stuff like that in the Philippines. They have rice, fish you know so I think that they need to work on that, but it's really hard to and another thing that bugs me a lot of the time is when people say that they are saying that they are coming out with devices that are bi-lingual. That usually means Spanish and English, but bilingual means Chinese and English, Chinese and **TaGolive**???? Chinese and something else, but when they say bilingual it's Spanish and English. That kinda offends me every now and then

AJ: And they don't take into consideration different dialects for African Americans is very important to be able to code switch. That's one aspect you can't live without but what device have we seen that would allow you do that.

DS: Even those devices in Spanish as far as I know

they're not even

DS: they're not even, no there just hopefully complete translations

JA: We're so proud, that oh we have this bilingual device

DS: Which is totally useless in a regular conversation because there're just complete translated from English the phrases won't even make sense

SS: A manufacturer won't develop a product which has no market potential so here I mean minority just will be ignored.

AJ: But I think the manufacturers are giving what the profession will allow it to give I think if we say do you know well let's think about his as a team. What you putting know is not communicatively valuable or it not gonna be communicatively effective then they would have to speak to that they would have to look at that because as the clinicians are gonna prescribe or suggest that these people actually take a or receive a device so if we can't stand up and say you know what your putting out it can work if we make these type of changes, if we incorporate this. then what are we doing to effectively serve the people that we represent I think some of that responsibility falls on us. That like the world can give you anything, but you have to shape it and mold so that it's effective to you. And we represent them for right now when they have no means of communicating so we have to be willing I like that device but if you could make these changes it would be very suitable for the client that I serve.

DS: and they're doing it also out of the need that they keep hearing- Well we need multi-cultural, that's what they hear, we need bilingual, oh, oh Hispanics is their first thought.

AJ: We're gonna add color

DS: And what we're gonna do is use this computer program that will translate everything from English that we have right now in English database into Spanish. And here it is. You know, very simple, very mechanical, very logical, but very uncommunicative.

JA: But like said it commercial.

DS: .right

JA: I mean they're out to make money.

AJ: right

DS: yeah,

JA: So it's to bad

right

DS: but I mean because it not functional.

right

DS: and then they probably the reaction well I gave you Spanish, what's they problem now?

AJ: Well we can say What's up?

H: Well the night is getting late, and you all have been wonderfully communicative. I will add some notes as the moderator, but before we turn off the audio tape or video tape if there's anything else that you'd like to send in the way of message to Dr. Parette and his group or to families in terms of information dissemination families and process they go through to select devices and then receive those into their home from a multi-cultural perspective in particular this would be a good time to send it. If not we'll wrap up and call it a night. Any last words?

EM: Do you want us to comment on the questionnaire at all?

H: You can do that if you'd like to.

EM: I felt that the question was to long

H: okay

EM: It encouraged answering no to avoid having to write lengthy answers

H: okay

DS: and even though we realize that there are subtleties in each question when your addressing question about within the family or questions about the community they just felt like it was the same question being asked over and over. It was just frustrating for us and we know we have to do questionnaires, so I could just see a family coming in and getting almost suspicious why are you asking these questions over and over again. I mean I just would be frustrating.

H: The consent form demographic for information form that was all comfortable, reasonable? Aright thank you very much, it's a lot of good information and a lot of good conservation right down to the end. So we'll call this a wrap, I'll add some notes as I kinda reflect on this, but certainly on behalf of Dr. Parette and his project and also as students I really appreciate it. This was fun and communicated through several tapes.

Focus Group with Related Service Personnel

April 17, 1996

Debra Reichert Hoge, Ed.D., Moderator
Southern Illinois University-Edwardsville

Summary Background Information

Type of Group: Structured Interview with Parents of Children with Devices
Date Conducted: 4/17/96

Where Conducted: Augmentative Communication Lab at the Arkansas Technology Resource Center at Arkansas Easter Seal Society.

Number of Persons Present and Roles: Bonnie Holmes, mother of 5 year old son who has cerebral palsy and uses a Delta Talker, **June Simpson** and **David Simpson**, parents of 7 year-old daughter who has schizencephaly and uses a Liberator.

Logistical Issues: Three more parents were scheduled to attend. We scheduled approximately 2 weeks before the groups and called to remind a week prior. Those present are all Caucasian parents who have adopted African-American children.

Synthesis Statements

1. Family goals and expectations for AAC
   - to understand children
   - provide choices
   - 2 types of families
     1. those totally surprised
     2. those with preconceived notion
   - many families uncertain about what device will be able to do
   - families of lower functioning students may:
     3. have higher expectations for devices
     4. expect immediate results
     5. have to contend with slow progress on part of the child
   - information for families is important:
     6. need to understand capabilities of devices
     7. need to understand how device will contribute to an enhanced quality of life for child
   - families expect that language will be present on receipt of device

2. Changing goals and expectations
    - families don't understand that AAC is unnatural
    - perceptions of AAC change
    - families have difficulty weaving AAC into lifestyles
    - for children with medical needs, families should be helped to see how AAC is related to medical concerns
    - families need to understand that AAC is only part of total communication
    - some families may feel that AAC will inhibit children from learning to talk
    - cost of AAC devices gives illusion of total communication capability
    - Memory concerns may limit what can be programmed on device

3. Role of families in AAC decision-making
    - families should be involved prior to purchase of devices
    - information needed from families before AAC device selection:
        8. clarification of family expectations of device
        9. language to be used
        10. goals regarding AAC device
    - involvement facilitates feelings of ownership in the process
    - failure in process results if families are not involved

4. Professional concerns regarding families
    - families should have realistic expectations
    - parents give "power" in decision-making to experts
    - families need to have ownership in both funding and information

5. Culture and AAC decision-making
    - Hispanic fathers tend to be more involved in funding and insurance issues
    - Hispanic mothers are involved in AAC implementation
    - Hispanic mothers provide more background information during decision-making
    - Decisions regarding Hispanic language should be based on who primary caregiver will be in future
    - African Americans have concerns about how child looks when using AAC devices
    - African American families focus on keeping devices clean
    - African American families are concerned about prestige of using devices
    - African American families are very protective of AAC devices
    - African American families may not want to use AAC devices to fullest potential even when opportunities are present
    - Accent is important for African American families
    - African American moms should assist in training pragmatics when standard vs. slang language is programmed onto device

- When two forms of language are programmed, increased cognitive load on user results
- Religious activities affect programming decisions (available memory, language used, frequency)
- Family may view prayers as more important than other community activities
- Professionals and families may need to reach middle ground when discussing cultural issues
- Language that is important to the user may be single most important consideration
- If children decide what is to be programmed, AAC device may become a cause/effect device
- Child desire to use certain phrases (when upset) must be balanced against pragmatic usage rule understanding
- Children have the right to express themselves
- Families have right to assist in choosing how words are to be expressed

6. AAC and community concerns

- Others may be drawn to child who uses AAC in community
- Mounts may not be transportable in cars so families won't use
- Families may fear dampness in community settings
- Families need to be shown how device can work in community
- Planning prior to going into community is important for S/PH children (planning for success)
- Families may leave devices behind to control emotional outbursts
- Therapists should help families understand what is possible with AAC
- People in community are accepting of technology in general
- Funding AAC usage across community settings is problematic
- For some children, issue of medical necessity and funding may not be linked to community usage
- Families may use AAC strategies that other are not familiar with
- Families should be made aware of AAC options across settings
- Training in multi-modal response modes may be necessary

7. AAC and the home environment

- Families have many initial fears:
  1. how to use devices
  2. when to use devices
  3. fear of device damage
  4. fear of child's abuse of device
- One parent often assumes responsibility for maintenance of device
- Families must assume additional responsibilities related to AAC
- Some families want to transfer responsibilities for AAC implementation to schools
- Roles of family members in AAC implementation vary

- Fathers find it easier to use AAC systems with which they are familiar
- Siblings should be empowered to use AAC devices appropriately:
  5. model and explain appropriate language usage
- Children are interested in AAC but don't understand its importance as a communication tool
- Funding for AAC is a stressor for families
- Maintenance is not typically considered by families
- First birthday party is a significant event for family:
  6. can result in lost dreams
  7. child may fail to perform as anticipated
  8. need birthday page for system
- Extended family members need training in AAC
- AAC device has many roles for family:
  9. child self-management
  10. community living
  11. recreation/leisure
  12. vocational

8. Working with professionals

- Families should not have preconceived ideas regarding AAC
- Families and professionals should be open-minded
- Families should clearly specify goals for their child
- Families should examine a range of devices
- Families must be able to accept their child's future inability to talk intelligibly
- Families must accept their child's disability
- Families must be patient (may want quick results)
- Families and professionals may assume defensive postures
- Families must be willing to commit time to AAC implementation
- Families will display varying degrees of willingness to participate in AAC implementation across time (acculturation)
- AAC success is linked to time commitment given by families
- Professionals should not use jargon
- Professionals should gear language to listeners
- Professionals should build trust with family members
- Professionals should collaborate with family members and build consensus
- Professionals should meet regularly with family members
- Professionals should celebrate the positive daily changes with family members
- Professionals should maintain open lines of communication and share information from across settings
- Professionals should value family insights
- Residential staff who work with children daily can provide insights

- Bonds between child and family exist even if there is no regular contact
- Professional involvement in institutions is linked to AAC success
- Child factors may be more important for AAC success for some children than parent commitment
- Families should be matched to demands of AAC devices
- Families of children in institutional settings will be limited by financial, educational, and physical constraints
- Family support groups may be important means of social support

9. AAC and funding
   - Funding may be easier for low-income families and harder for middle class families
   - Schools have concerns regarding limited funding
   - When devices belong to school, families should be informed
   - Cooperatives may be used to purchase devices, thus minimizing disagreements across districts
   - Smaller coops are needed to serve school districts
   - Cooperation is needed across service settings during transition to assist in funding

Transcript

My name is Cheryl Nessum. I'm a speech pathologist with Belleville Area Special Education District.

My name is Rochelle Cox. I'm an assistive technologist with Belleville Area Special Education District.

My name is Rosalie Willike. I'm a speech pathologist in private practice in the St Louis metropolitan area.

My name is Frances Justice and I'm a speech language pathologist in private practice.

I'm Debra Reichart Hoge I'm an associate professor in speech pathology and ideology here at SIU-Edwardsville.

My name is Scott Everhart. I'm a speech pathologist with the William Achievement and Development Resource Center in Wood River Illinois.

My name is Celeste Stratemeyer. I'm a speech therapist at Murray Developmental Center in Centralia.

My name is Barb Cardwell. I'm a speech language Murray Developmental Center in Centralia Illinois.

DH The first question that we want to pose is what do you all perceive the goals or expectations to be for families and children who want augmentative devices but have not yet received them? So we'll pose that initially and then encourage within the discussion the kinda goals or expectations that you see changing after families have received their augmentative devices and in what ways those goals and expectations change.

RC The thing that I hear from families a lot is I'm really tired of trying to guess what my kid is trying to tell me. I want them to be able to tell me what they want so that I'm not limiting their choices to two or three things. That they have a wide spread variety of things to talk about and they can initiate conversations in our family.

RW I see that perception also. I think I see basically two types of families. I see the ones that are totally surprised that someone would recommend an augmentative device; suggesting that there's some communication in that child and they're just not able to get it out. So I see those families that are totally surprised at the recommendation and then I see families that have their preconceived notions about what they think augmentative communication can do for their child. And sometimes that's right on target and sometimes they're at a point where they probably need a lot more information before they can truly see what the capabilities would be for the child with an augmentative device. So I see those two types of families.

CN And I think sometimes they're very surprised by what the child can do and sometimes they're-they anticipate things that we may feel are unrealistic but you really don't have an idea of what will happen until they actually have an opportunity to try that. I think that's the important thing-there's that anticipation of will it work or won't it work. How much will it open my child? How much will I be able to communicate with my child?

SE I work with the severe and profound population. I think the higher functioning the student the more realistic the expectations the parents have. I think the lower the functioning of the student the less realistic, the expectations are much less realistic because they seem to think that this device is going to immediately be used effectively. That they will have an unlimited amount of vocabulary immediately put on the device and that's not so. With the sever and profound population, many times it begins with just a cause and effect kind of teaching tool and with one picture. It might be six months before we advance to two pictures and I think that in my experience that's been the most common problem. The parents wonder why we're not moving along quicker than we are.

BC Aren't those goals initially based upon probably the information that we do give them in making sure that they understand what's going to be happening in the process. Their goals may be set to high if we don't give the right information possibly.

FJ I think that it's our job as professionals to initially when we present the idea of augmentative communication and augmentative communication devices to a family that we let them know what the capabilities of communication devices are. What these devices can allow their child to do and hopefully give them the knowledge that what this device is going to do for their child is improve the quality of that child's' life.

SE And with a child that has no communication skills whatsoever or very little communication skills just being able to ask for one thing is a major accomplishment for many of them.

RC That brings up a good point, sometimes and maybe me being the only non-speech language pathologist on the panel. You kinda expect that language to be there when you get the device that it's gonna all magically gonna fall in place. I've really learned working with Cheryl and other professionals in the field that's a whole learning process in it's self that's gonna happen with the device. I think that we kinda expect boom there it sits let's go and sometimes that doesn't always happen or we don't put it at the right level.

RW I think also parents perceive what life will be like with one of those devices. They may have had some exposure to devices through the media or through other people or that kinda thing. They have some notions about what life would be like and as someone mentioned before that a child would simply be initiating communication if the device is there I will communicate type of thing. Not understanding that it's a very unnatural kind of communication it's cumbersome in many cases, but when you take child who is totally unable to communicate and it's the only avenue that's what happens. That does change after they get the device and begin working with it that perception quickly begins to change and you get some parents who were really advocates of getting the device and getting it up and going who really start developing some doubts early on about whether or not that's really something they can work into their family life style and whether the effort is worth what you get.

CS One thing that I though about was that while communication is probably foremost on our minds in a family situation maybe their main concern for their child is medical, or and it may not be communication. So then this may just be adding to their burden and we have to help them see that it can help even medically for that child to be able to communicate their needs

RW I think another thing that happens is that parents perceive augmentative communication as an either or proposition rather than the fact that the augmentative device can be part of the total communication system and that's just part of it. I think that sometimes that effects their beginning perceptions of do I want one of these for my child do I want to hook them up to a device like this and then they'll never speak. That's another perception that many parents have is, if we give then a device they'll never speak. So I think we have those kinds of preconceived notions also early on and I see that evolve into a more realistic understanding of how this is part of a total communication system as time goes on with training and involvement.

SE I find that with any form of alternative communication whether it be the communication boards or the sign language is the fear that their child will never be able to talk and I don't see it stopping with age either. I think that no matter whether the kid is two or twenty there is still that hope that one day he's going to say some words or be able to converse with me verbally. Your right the main objective early on is to convince the parent that it's not an alternative period that it's only an assistive type of technology.

RC Don't you think that the cost kinda gives us that allusion that if this thing is gonna be this expensive that it must be take everything and so we gotta go with it with all our force and if the speech does come or some other alternative we've really failed cause we've spent all this money but really it's just another tool that helped us. The cost will come down like everything else in technology.

SE The communication devices that we have the majority are IntroTalkers and they were not purchased by the families insurance company or by private organizations. They were purchased by a one time only funding program that the state of Illinois had and we were able to get about 30 to 35 IntroTalkers at one time. They were bought for the students. They're not the schools. They were bought for the students. So the problem we had was that parents were totally unfamiliar with even the concept of a augmentative communication system. This was not- they did not play a role in the purchase of the device so there was no counseling prior to the purchase, no discussions of this is why this device is important. We simply went through the list of kids and the professionals decided which students would benefit from a particular communication aide and that's how they were purchased. So we had problems with the parents excepting the device and they already had it.

CN I think one thing that you hit on that's real important for us and what we've learned along this road is that involving parents from the beginning. One of the questions we always ask them is what do you want this device to do for your child? What do you want them to be able to speak in every situation, communicate basic wants and needs as you were talking about. What are your goals for your child? Whether we think their are realistic or not to have this parent as a member of the team before we start an evaluation. To know that they are involved in that process all along the way it doesn't seem like it comes as much as a surprise at the end. That it's gonna require training and that it goes on because our evaluations take a long time and we spend months with these kids before we do that. So it's not like the parents have never heard of it until it there because we request strongly their involvement from the beginning.

SC I didn't have that involvement.

BS That's a big plus for us.

FJ Don't you think that when parents are involved in the purchase and seeking the funding, and finding the funding or even taking that money out of their own pocket there is a lot more ownership in that communication device. They are very dedicated to seeing that this works for their child.

SE And then we really see the expectations.

RW That's right. There have been a couple of studies done along those lines. What make a communication device fail? One of the things that came up in most all of the cases of failure was that the parents didn't have any involvement in funding either seeking it or adding to the funding themselves. So it was very interesting.

DH Okay we've talked a little bit about the roles of family members during the augmentative decision making process from a point of view of being included as part of a team members, discussing parts of their funding, finding funding, going along with funding, filling out paper work, etc. What are some of your greatest concerns that you may have encountered in working with parents during that decision making process? Funding has gotta be way up there just because of the cost of the devices.

FJ I think one of the things that we talked about earlier has continued to evolve as a concern and that is how realistic some parents are about what is device is gonna do for their child. It all comes back to us having to work very carefully with the parents to say this is what this device can do for your child.

CN I think too, one of my concerns is that we offer - they view us not that we view ourselves as the expert these people know everything about augmentative communication. Therefore, the parents are at times less apt to project their own thoughts, feelings, about those things initially at least. Feeling we'll pick the best device and oh yeah we'll just go along and that again even if their are involved in the funding if they don't feel that they had a chance. We try as much as we can to give them a chance to look at different devices. Talk about the capabilities of different devices and what their child could and could not do with that device so they feel more informed and therefore more comfortable. Therefore, again the ownership of it financial as well as informational I think is important for the families.

DH From a cultural perspective do you see any differences in what you were just talking about across cultures? That you all may see in the school district in terms of ownership, willingness to be trained, etc. And it may not be but we need to throw culture in here to so Phil gets some data.

RW I have a client who that is Hispanic and I have found that in that culture that the fathers roles is to oversee for the care and financial security of the family and but he doesn't really have any role in the decision making as far as what device, what is to be said on the device, how it's to be used and that kind of thing. The mother really takes that role. I'm Hispanic myself so I know that's pretty typical of that culture and so it can validate my own impressions of what I was seeing with that client. The father is heavily involved in the funding and the finances and the arguing with the insurance companies and that kind of thing. While the mother is the one in the background being the implementor and she really was the one who pushed for the device in the first place. I see him taking a backseat role in the daily implementation and that kinda thing. That's between the women.

RC I think that true too. What we see is we do see a few kids who are either under school age, or under three, or over 21 and you find that the family unit as a whole it does tend that we end up more with the mothers than the fathers in terms of implementation of the devices. They seem to be the ones who are able to give you that information of oh, when she turns her head like this she means that, and those sorts of things more that they tend to serve that nurturing care giver role more often I think.

FJ I don't have a lot of experience across cultures with augmentative communication but I have worked very closely with one African American single mom and the things that were happening with this mother was more of what you were talking about. Where mom is the single care giver, mother does everything, mother goes to all of the appointments, mother made the request for the communication device, and she carries and shelters the whole burden and it's a big one.

RW I've also found in some of the clients that are Afro-American that they are very concerned about how the child looks with the device, probably more so than some of the other cultures that I've worked with. They're very concerned with it appropriateness and how it looks and that it's kept clean and that it's a pretty prestige presentation. Almost to the point where they would not have it as available because it had to be kept clean and it was hard to get and they didn't want anything to happen to it and very protective of the device. In some cases the parents did not use it to it's full potential even when the opportunities where there but if it were left at school by accident over night, or if there was a manual that needed to be borrowed or something like that they were very possessive of the device. So probably a hard fought battle to get it or they understand how difficult the funding is or whatever. I have seen that not across cultures, but pretty specifically to that African American culture.

DH Speaking of that and talking about how children look with devices and portability etc. Let's visit the issue for a couple of minutes about family members of children with disabilities with aides out in the community as far as community access, the main stream of the general community. Can we visit on that for a little bit.

CN My favorite topic here we go- I think there's a number of issues that come up one is the looking different issue, one is the access you know when parents know again how much they cost, how much they can do, how important this is to their child. Well if you think they're gonna leave it out in the rain while they go from the van to the restaurant, they're not they won't, so when that child rolls in and see his friend coming out the door he can't say anything. The looking different issue sometimes viewed by families a negative, sometimes it's viewed at a positive because everyone is drawn to that child. Look at him he had the coolest thing I've ever seen. That sort of an issue is there too. Some of our families find them to cumbersome especially the larger devices you can't put the mount in the car and all this in the van at the same time. This isn't safe, I'm not willing to do that. So I think that when we go out into the community and their less accessible were not doing as much as we can for those children at that point and those families to help them feel more comfortable that they can know that this can get wet and still work most of the time.

FJ I think that one of the answers to that and working privately maybe I have a little bit more opportunity to do that is to take your clients into the community for therapy. Show the parents and the families how this can work and how exciting it can be and how their child can communicate in the community with their communication devices. I had a phone call from a mother the other night that told me that she had taken her little girl with her communication device mounted on her wheelchair to Wal-Mart and they were communicating about their purchases about what she wanted, what she liked, what she wanted to go see next, and she had another mother approach her and say what a wonderful thing. My little girl was nonverbal and how could I see about getting one of these for my daughter.

RW I think there is a lot of that.

SE I think in the case of my population the problem is often we don't often have the vocabulary on there to meet the needs in this particular situation. So there is no need to take the device even though hi may be on there and my name is whatever. Which can be used in any situation because there's not vocabulary specific to let's say a ball game or a going to the store, then it's not taken. I think a big part of it is embarrassment, I really do. I think that when it's not taken it looks so different and it stands out so much that I think parents I don't want to generalize but I think many parents would like to just avoid that confrontation with others coming up to them.

RW I think in the population that your working with Scott, we work with that population also. Individuals who function at a severe and profound range learn in neat little packages. They learn in activity based kinds of situations and when your going out into the community if that is done without all of the proper planning and layout. What's the dialogue gonna be like, that sort of thing even the first round even with very meticulous planning for success as far as picking the correct dialogue and that sort of thing that individual has never encountered that communication device with unfamiliar listeners in an unfamiliar setting. So your always gonna get probably behaviors inappropriate behaviors and that kind of things. I think that something that can be dealt with through therapy and something that families - it's pretty common sensical to those of us who work with this, but families that's not their job to be thinking about how to implement and that kind of thing. So just bringing it to their attention about the planning of that activity and looking at it as a communication activity. Okay you want to go to Wal-Mart, you want to take the device? Let's plan it for success, when is Wal-Mart the least busy? Is their a listener in there that you can go in before hand and talk to and inform them about how to be a listener to a person who uses an augmentative device? Can you tell them what the dialogue is likely to be? Then if that kind of thing is done then in those situations I see the parents more likely to use the devices in the community. But nevertheless with your learners who have severe and profound disabilities every activity is going to have to be scripted like that before hand and you can't really expect the generalization of skills like you can with individuals who don't have cognitive impairments of that nature. So that kinda interesting.

CS I was just gonna say that one of the things we noticed is sometimes our staff leave a device behind on an outing because they say we're going to the movie and we didn't want him to talk or we were gonna go to church and it wasn't a place for him to talk. Of course, we all know that we won't do that but I think that one reason they just think ahead and think we just alleviate any problems with him speaking out at the movie or at church.

SE I've heard that also.

RW I think that part of our job as therapist is opening parents up to the possibilities of what can be done. The opportunities for appropriate communication and bringing to their mind another common sensical thought that do you not communicate at church? Do you not smile at anybody? Do you not wave at anybody? Maybe the device won't be the appropriate thing there maybe that's where you would have to kick into a gesture system or that kind of thing. I think that's part of our role as therapist is to help parents to outline those situations so that they know what's feasible and what not but yet showing them what the broader boundaries of that are and that they are almost limitless if you really script the situation and do careful planning. But that's real true of support staff they don't see the whole picture some of the times.

BC Or make some changes in the device to make it softer and valuable so you can still whisper or whatever. There was another point that I was gonna bring about I though you know with all the lap top computers, a lot of electronic devices out and people are walking around carrying or sitting or working at them. You do see a lot of electronic devices out that are with the normal population. So you know if someone else if using their communication device out there it's not quite so like it was 10 years ago so unusual.

FJ One of the issues that comes up with me on a regular bases is with clients who are ambulatory and how heavy is their communication device, how long are they going to gone, who is going to carry it, who's gonna have the responsibility for it, is it gonna get set down, left somewhere, or is gonna get set down and someone else is going to play with it and I think that one of the things that has become available recently are the smaller communication devices with a more limited number of communications in them that can be programmed for short trips into the community. That are a wonderful substitute, but when you start looking into those things your looking into funding and what funding agencies are going to fund a Liberator for situations where an individual can be seated and working or have his communication device on a table at home and he can run over then say a Parrot or something like that, that they can strap on themselves take into the community easily. It's not gonna happen.

RW Not very easily, they'll look at that as not medical necessity and that kind of thing. Do they really need to go into the community is that a medical necessity? So we run into some funding problems with that.

CN I think too that before we leave the family issue, one thing we find when your working with devices especially with older individuals. The family has a communication system they use and they can read that child when they go out into the community and anticipate so well that they don't see as big of a need to use that as maybe unfamiliar listeners to that individual do. They assume that everybody can read that eye blink or whatever.

SE It's easier, it's easier to rely on that.

RC I think that the big picture is that we just need to help families look at ways for the child to communicate out in the community in a real total communication look because it's not a decision of whether or not we take a look at the device but what is our list of communication techniques are we gonna use in this situation. I think that if we keep that in mind and help our families focus on that, they'll take more risks to take higher level devices out as they get comfortable with them.

DH That may go back to a training issue too. We talked a little bit about looking at the augmentative device as either or. This is it. This is your communication device and I haven't heard the word multi-modal come up yet, but I keep hearing gesture, facial expression, eye gaze etc. and perhaps that a training issue we all need to be cognizance of with our families is to really talk about those various nuances that they can read that others should be able to and we can train those in addition to the actual use of the device. Okay, think know about the organization of the home environment, the relationship with family members and the levels of stress that might be encountered in home organization, family relationships, and levels of stress when that device comes in. I think that is what we're pointed at here because we have talked about expectation before you get one and after. So let's talk about now the realities of having that device stress, home organization, and relationship between families. We've touched on that a little bit with mom being basically the day to day care givers and other folks being mainly the decision maker.

RW My experience has been when the device comes in they get that device to me as fast as they can. It like here it is what do we do and it's almost a scary kind of thing. So we just have to methodically introduce it and that kind of thing and we go through a series of steps where it's a methodical and very gradual process and assuring them that it's a gradual process and that there are no failures in this. There's just adjustments that need to be made because something doesn't work in one situation we look at that as a learning thing for us. That child is going to teach us how well they can use it. So I see that initial fear and overwhelming feeling about how to use it and what to do with it and fear of damage and fear of the child himself. That's an awful big one. They'll break it. They'll drop it. They'll push a button they're not supposed to. Who's going to be the programmer? Who's going to manage the system? and I think initially those are the kinds of things that they want. What are we going to do with it? Who's going to manage it? What's the feasibility of the transporting and getting it set up?

FJ I find that usually one parent takes the responsibility for the communication device. Programming it, making sure if this student, if the child is unable to do it, making sure that it's charged, making sure that it works and even making sure that the child has the opportunities to communicate with a communication device and that is a huge time commitment on the part of that person.

CN I think that there are absolutely stresses on the family. I think there no question, in addition to here's you device and all these doors it can open there are also a number of our students that pretty constantly deal with medical issues. So I think it goes up and down in priority at home. I think there are times when it becomes one more thing that I have to do and I think that a big stressor on a family. Especially we deal with a number of single parent families and I think just the entire thing that they carry on themselves. It's like we've just added one more. Working in the school systems they're often much to willing to say, "here school people you do this and I'll charge you that night and when you get it all working then we'll work on it." To back off of that. There are times when I can understand that because they are dealing with so many other issues at home. And I think that's a significant concern of theirs.

FJ I worked with one family that had a really nice orientation to the whole thing. The dad took care of all of the mechanical things like the wheelchair mount, and reading the manuals, and making sure he knew how everything worked. The mom did a lot of just the facilitating the use of the communication device in the home and making sure that her daughter had the overlays that she needed, and all the things she needed to say. At that time we were starting to develop that, so she we helping keep me current on the things that I needed to get ready for. Then I worked with another family who mom did everything. Mom did the programming. Mom got the communication device. Mom saw that her daughter used the communication device at home and gave her the opportunities to do that and nobody else was paying a lot of attention to it. It was a tremendous stress on the mother.

CN Did you see any changes in the roles in the family between the parents? That to me would be something that could possibly cause stress in the family?

FJ At that time, no I don't think so. I think that this was traditionally that's what this situation was with this handicap child is just that mom took care of everything. It was kinda like the situation Rosalie was talking about in the Hispanic family. Dad worked, mom took care of the child with the disability, and everything associated with that and when dad communicated with the child he went back to relying on the gestures and all of those sort of things because it was easier.

BC Have you found any of the older siblings their helping out or participating more or doing some of the work that maybe mom would have done or older siblings?

FJ I can speak about a situation that I have just been in recently and actually I think the child is younger but he does a lot of sitting down with sister and talking to her and playing games with her and communicating with her. We have to watch him because at times he'll say this is what she wants to say. It really can really be a good situation when siblings are involved and interested in taking on a part of that role.

RC I think that one of our jobs has to be to empower the siblings because we also have situations where the sibling aren't told about the device. They're not- I don't think they understand the importance of it so when this kid comes to school the next day you look at it and say okay who played with it. You know that a sibling has got in there and reeked havoc you know and had a great time playing with it, making it talk and it was exciting and fun. However, there has to be that healthy respect that you can use it and we all can use it to talk. That's great modeling to show people where thing are on the device but it's also a communication tool. It's not just a thing that we sit down and play on.

It's not a computer

SE That also happens with other children in the classroom

Group Agreement

SE They want to play if they don't have one. Not so much play with it but just see what it all about. They are very interested in it.

RW That's one of the stresses in the home.

SE Another stress too, is beyond the point where they get it is when something goes wrong with it and it needs to be repaired. That been a major stress area recently because many of our devices that we've had for about three years. Suddenly they're needing new battery packs. Suddenly they're needing new microphones. Many were thrown when we first got them and have been thrown many times since and so they're in need of repair. So again the funding issue comes in, funding is not- the price of a repair of a communication device is not cheap. So parents have that added worry and that added burden so again we're talking funding. I've gone back to variety club to have funding reimbursed. I've gone back to the child's' insurance company. We've had to wait a while until the parent had the money to pay for it. Seventy five dollars may or may not be a lot of money for some people. Sometimes were talking $150 to $200 dollars and then we're really talking about a major chunk that many families can not afford. So I think that's another issue all together as far as stress.

FJ I think that is something that families don't even consider when they initially think about purchasing communication device. How much is it going to cost our family to keep this device up and running and are we going to be able to do it? Cause there are definitely expenses involved and the battery is one of the main things. It will be going along fine for a long, long time then all of the sudden pow.(Made noise)

SE Exactly

FJ Then you've got a major expense

SE Many had expended warranties at the very beginning and they have expired so know they're having to pay for it out of their own pocket.

RC I hear other stories about the big first birthday party after they have the device. Have you guys heard this with the extended family? You know I think we do a good job of preparing the primary care givers family members, but then you know they're ready to go with the device. They've had the training their expectations are in line but then we hit the first big birthday party. Everybody goes and sits and waits for the right thing and either it wonderful and everything is great or the child doesn't perform in front of the crowd as everyone expected. Then it's you know it they're running after you know another lost dream and I hear that a lot. The frustrations of the family that you know the grandparents don't understand. The grandfather puts it always the minute gets there or they sit and hound the kid and try and get him to practice- you know that will make them better at it. So I think there is that whole issue of the extended family that we kinda throw parents out. We give them a lot of training but how do you explain it to other people in your family? What kinds of expectations can they have? How can you help them communicate with the child? I think that real important too.

RW That does need to be a part of what we do, if you can empower that parent enough in your training that they can know what to they those relatives and that kind of thing. Once again if you set those situations up for success and talk to potential listeners before hand and maybe target some people who are more receptive to it maybe just target the communications towards that end maybe the first time they get together and then maybe gradually increase the listeners that are informed it's a big job. I know I have a family that is huge and they get together for every birthday. There's like 15 cousins and all these nephews. Between now and April they have five or six birthday parties, so we're doing a birthday page. We're informing potential listeners and that kind of thing and the user is part of that. He's helping to develop the dialog that he wants to use at those parties and who he wants to talk to and that kind of thing. It really is imperative otherwise we're just teaching them to communicate with their family. If we look at communication devices for what they really are. It's really to increase that individuals independence in the four domains of life: self management, community functioning, recreation and leisure, vocational kinds of things. Anything we can do to get that device up and going to enable that individual to be more independent within those domains is going to be what we need to target ourselves for.

DH If you had a chance to offer families some advice based on your experience and part of this question has to do with the CD ROM that will be developed with our comments. If you had a chance to offer families some advice on how to work better with professionals and identifying augmentative devices for their children just from your expertise base. What kinds of things might you be able to tell families or share with families?

RW Could you repeat that?

DH If you had a chance to offer families some advice on how to better work with professionals when they are going to identify an augmentative device for their child. What kids of pointers might you share with them?
Break

Just before we took a short breather I asked you all to think about advice you might offer families on how to better work with professionals in trying to identify devices for their children and for their loved ones. I would like to hear from you guys too, about devices and family use even though your folks are institutionalized they still have family connections. So what kind of advise would you give families?

FJ I think that the most important thing that a family can do when coming into say an evaluation for an augmentative communication device with a professional is not to come in with a preconceived notion. I want you to prescribe this device for my child or we saw a Liberator in Exceptional Parent Magazine and I think that would really be good for my child. It think that they need to come in with an open mind. Let us take a look at the child. What they would like for their child to do. What their child needs to do and look at all kinds of communication devices. Not walk in and say I would like this for my child and if you'll write a letter to variety club they will buy it.

CN I think it's important that parents ask questions that they state what they hope their child will be able to do with the device. That they ask how that can be accomplished. That they talk with that professional and not be afraid to -- they know these children much better than we do. To say well you know because we may if we see them as school or in a certain situation we may only see them in their chair but at home they may never be in their wheelchair. They may be in some other position and if we get their switch mounted to their chair and got them all set up and it works perfectly here when they go home and if that's not where they are and they've never shared that with us we don't figure out why this doesn't work at home and those sorts of issues. Especially in our situation in being a school based evaluation sight I think it's important for them not to be intimidated by parents and it's important for us no to intimidate them with big words and letters, and names of devices- dynamic and static, overlay, and all sorts of thing that have other ideas of what those words mean. It's important that we gear our language to our listeners. It's important that they ask us questions and not be at all concerned and if we say something that does not sound right about their kid. I want them to stop me and say, "how did you get that I never see that, I never see that, or don't you know at home they can do it this way," those sorts of things. Sharing of information is essential.

RC And to build on that I think that we must continue to collaborate as a team. I think that you must insist that you meet regularly because if you only when it's a problem or the device is failing then it sets up for that defense, because either I'm wrong or your wrong if we not working on a team. You also need to meet to celebrate the good things that that happen because if you don't you kinda lose sight of the progress you make. I think that when you collaborate when something goes wrong or we have a portion of the device that's not working right you kinda are in it together. It's not your getting together -like they're calling again, there must something wrong and their going to blame us or we sit across the table things aren't working well at home. If it's a collaborative mode you just get together. State the problem and let's problem solve it out. I think the most important thing to keep the lines of communication open.

BC Even though we supposedly the experts they are with that child all day everyday or most of the day and they do have some insights or some ideas. Don't feel threaten like I've got this idea I would like to try this with the child. Their the parent and they're with them and they should know. They should have some recommendations and speech pathologist or who ever it is should except some of those ideas or recommendations. They are very valuable.

RW We have to have an open mind also. I think if the meeting takes the tone of a consensus planning kind of meeting where we truly are Rochelle said problem solving out. What is the communication problem? What resources can we offer from our professional background? Essentially it's pretty much a parent decision and I think it's our job to give them enough information to make that decision to the best of their ability and hope that we can reach a consensus on what's best for the use. That doesn't always happen and when it doesn't then there's usually failure somewhere with what's gonna happen later either the device will fail or whatever. It should be a consensus thing and to assume that we know everything if certainly the wrong road because I learned more from my parents and my users than I learned in my course work. So it really a learning situation.

BC In our situation, we learn more from our staff that work with our individuals because they're with them most of the time. We have to ask them questions to find out the information that would not get when we are working with or evaluating the individual.

RW Do your children- is it residential how is that to work with parents who are removed? Do they come closer when your looking at things like this?

CS I think they probably notice the leaps in their skills more than the parent who's with them everyday because they're not there on a daily bases. So they make a visit on their birthday and when they come back on Christian they say, "wow look at the explosion." I've noticed especially with one user whose parents bought him a device. They're really surprised. I think that how much he is able to communicate from visit to visit. It has enable him to communicate better with them long distance using a speaker phone he can talk to them with out relying on the staff to communicate to call mom and dad.

RW Now your individuals- do you have with serve and profound disabilities? How is that when the parent comes in as an unfamiliar listener?

BC I think that even though they're not with them on a daily bases, it surprising how well they still know their child or their young adult too.

RW That good

BC There's that bond there no matter how long it may be before they see them another time.

RW That's very interesting, that's an insight that I couldn't have. That's neat.

CN I think too you made a real important point, because we serve primarily as evaluation and follow up in our school districts we do not see our client everyday. So we will see someone pretty intensively at first and then we kind of turn it over to the speech therapist and the people at the school and we'll go back latter and it's like wow. They're like were just not getting anywhere on this, don't of remember three months ago you were at this point and know your here. I think that when your there everyday you don't celebrate enough of what you are doing. You only perceive again your problems and the gains that children and families make in this and working with families we do a family support group for different devices. So that families, teachers, anybody that wants to come basically can come and use that as a time to share. I think the more you see the teachers and the parents interact outside the classroom because we don't do them at school we do them at our office. So it's outside of their classroom building, it's outside of their school, not in their district. There is a different interaction there and they can share what they see not everyday not like the notebook that goes back and forth so they have a different perspective when they come to those situations.

DH That's really interesting because that one of the issues we need to go back to and think some more about is the issue of culture. We've talked a lot about ethnicity in culture, but the institutionalized population is a completely different culture. I think we have gotten some insight to that and how families operate within that kind of a setting. I want you all to think a little bit broader about culture. Let's think about religion and how that may play apart of culture, social economic status and maybe some changes or differences that we might see in families of these various aspects of culture with children with disabilities using augmentative devices. Francis you started to say something about programming a device.

FJ I think one of the issues that has come up with religion is that are we going to program prays into the communication device that can take up huge chunks of memory? When you only have a small amount of memory or different and I'm not even sure what all these things are - different things for conformation and that sort of thing. Sometimes we have to talk to parents about let's look at how much of the memory this is going to take up and is it really going to be of that much value or are you going to have to use it that often or is it something that maybe we can put in now and use a couple of times. Then get rid of it and favor it with some of the day to day things your child needs to say.

CN I think that's a real important issue, we have a child who uses a Liberator and you can scroll back through and see what has been said over the weekend. What we find is the only thing that is used over the weekend is the prayers and if that's where the family's' focus is then I think we need to be sure that we respect that. If the most important thing outside of school is church. Then that's where our focus needs to be rather than putting in the McDonald's page. Although I the McDonald's page would be very important to that family the most important thing maybe that they child is able to participate at that one moment in church on Sunday and that may their only reason for having that device and I think it's -- although it may not be the way I want it I certainly think that if this device is for this child to communicate as part of that family. That those family values are real important. Sometimes it's hard to step back from your values and say this is the most important thing to them. I think that's probably one of the hardest issues I have is what's most important to you, now let me tell you what's most important to me. Okay now how are we going to come to this middle ground?

FJ I think that ultimately what's most important is what's is most important to the user and that's it. That's it. Why have five things in the communication device with very limited memory? Say an Alpha Talker opposed to a Liberator and not have anything that the user really cares about saying.

RW Well, I have seen users who did not have therapeutic intervention but got a device without a therapist and they began programming in things like that. What it did was compromise the little boys ability to every look at that communication device as a communication device. That's been two and a half years ago. We are still trying to get him to use it with communicative intent because he learned to hit it and hear book pages read, prays, long orations about what he did over the weekend that were not even in his linguistic ability to understand. It became like a cause and effect device. So I think it's our job to temper what parents want in there and again look at what the user needs are, what the implications are of putting something like that in and how it might effect further the use of the device. If you have a person with normal intelligence you know who wants to do that sort of thing that different, but you really need to look at your user. I really feel like its our job to inform the ramifications of what we put in the device and how it used communicatively.

CS We also get into language and some language that the user may desired to be programmed on their device may not be acceptable to the parent and that is a real hard issue. It's a real hard issue at our institution because sometimes this adult person with cerebral palsy would like to say a few words when their upset. Then the residential manager says we can't be saying those things. It becomes a cultural issue because it's accepted in our culture for an adult male to say some things sometimes.

RW What's least restrictive and what's not?

CS Right, it's been hard.

CN I think it goes back to that issue you said before we just don't the device when it's gonna cause us problems. So if those are the things your gonna say then we'll just turn this sucker off and that's not fair to them.

Group Right, right

CN Just because you don't have a voice output doesn't mean that you can't have the right to say what you want to say.

FJ I think that with those sorts of things, that it's my personal feeling, that if that person wants to say those things that those things should be available. They should be taught that you might be able to get away with saying this here but you can't in school. You can't do this around this person because they will be offended.

SE I have a mild example, it has nothing to do with- the student that I'm thinking about could use this phrase anywhere. Where parents are involved I have one parent in particular who helps me choose how to say a certain phrase based on how well she knows her daughter personality. For example, when I can say her first name- when Michelle is upset about something. Mom wanted on there -she wanted Michelle to be able to express that anger because Michelle was doing it in inappropriate ways. So I put on the device I am so mad, okay. Mom wrote back or called back and she said, "Don't think that Michelle would say it quite that way, okay she would probably say umh" and it was the way the phrase was recorded also. A female friend of mine said I am so mad. Mom said no, "Michelle would say it I am so angry." So we recorded it that way. So I think that just how a phrase is said or a choice of vocabulary is an issue and parents play a role in that area too.

FJ I have an interesting example from that stand point, about how things are said. I was working with a client who is African American and has a huge family with very unusual names. We had the task of putting all of this family- this happened to be a communication device with a large memory. We had lots of memory to use. We put all of his family all of the important people in his family names in the communication device, but the unusual pronunciations it took a tremendous amount of time because we had do pronunciation exceptions for all of the names. So that's something else your getting into culturally.

RW And also I think with one little girl that I worked with of African American decent, it was important that I work with her mother about dialectal kinds of things. How we wanted that in the device and ultimately it was her decision, but I gave her some information about typically how dialect in handled in children who are verbal. Then she made the decision programmed and the little girl also had a part in that. It was a really neat interaction because the little girl said the way she wanted it and then her mother would explain, "yes, but when your with these people you can say it that way, but when your these other people you will need to say it this way" and that kind of thing. So that was really - I could have told her that but probably won't have meant as much as her mother and also she had an older sibling there who was telling her that you can't say that with those people. You have to say it the way mom said to say it.

SE So you had the same phrase programmed in the device two different ways.

DH So there was code switching available. That's great.

RW Some devices can afford you that and some can't. That's just one of the things you take into consideration in you evaluation too.

CN It's a little more cognitive load on the user

RW Yes it is, yes it is

CN It gives them choices.

RW Right

DH How about social economic? We haven't talked about socioeconomic factors at all just yet. We've talked about culture in terms of ethnicity, religion, gender we visited on gender. Funding has got to be a part

FJ I have a comment about that. What I have found is that for individuals in the lower socioeconomic groups it is the easiest to find funding for communication devices. Your people who are wealthy can afford to go out and buy them. Your people who are really hurting quite often are your middle income families. Particularly your middle income families who have children with disabilities that have Maxell out their insurance plan. The insurance plans are not will to pay or offer anything toward a communication device. I think in this immediate area we happen to be very lucky that we have variety club in St. Louis who is willing to help us with some communication devices but if you get very far out of this area it gets increasingly difficult for middle income families to find funding.

CN I think too, when you start to deal with those issues and you have to look for those other funding sources and your starting to look at churches and civic organizations and things like that is a real important time before you start any of that to talk with the family. How do you feel about this? How do you feel because their child will become a focus of a fairly public place and that not always somewhere they feel comfortable. I think middle class people too are probably the most stuck group in terms of funding. A case that comes to mind involves a family that runs their own business and they have two children with disabilities. This one is the older of the two and they know that down the road that this other child is going to require the same level of care and things but doesn't need it yet. So now do we buy one device that could work for both of them those are the kinds of things they've approached us with. When your thinking in that perspective that makes absolute sense, but these people are self employed, self insured. They're in a tough boat.

RW What is the schools role with you as the evaluator and you making recommendation as to what kind of equipment they would need. What is the schools role for these families who have no other means of funding?

RC For us as we get closer to the end of the evaluation, as we are having our team meeting discussing it. We start talking about funding issues at that time we lay out to the parents you have a variety of sources you can go to. You can go to insurance, Medicaid, funding outside, and your school district is another one of those sources. We try to lay out the pro and cons of the school districts buying them. We happen to be in a very mobile community because we're right near Scott Airforce Base. We have families who come in for a three year period and then their gone. So we look at that kind of situation. We look at how where the kids are, is this going to be a stepping stone or is this a device that's gonna handle it all for seven years. Those kinds of decisions-and we offer advice a lot of times because parents look at you like- what do I do. I think a lot of our parents realize that the school district are in a bind to because six thousand dollars, seven thousand dollars for one student that there is no budget for a this point. A lot of times you go to our smaller school districts, who may have- I can't even think of the smallest school district we have. They just look at like where are we supposed to get this money from. So I think parents are cognizant of both the issues but as far as our school district is concerned that if a child does need a device the school district is an option.

FJ When I'm working with parents I think that it's very important that they know up front that if the school district buys that communication device it does not belong to them. It belongs to the school district and that is always- I always tell them that because they need to know it. When their child becomes 21 leaves the school or when their child leaves the school district they've got the same effort in from of them again to procure a communication device.

CN And if it's a device that's programmed just for that child.

That's right

RC And it an issue when you get to looking at the reason why you have an device in an IEP is to look at the adverse effect against education. Well those issues can really become a difficulty when your looking at what vocabulary goes in there because we're looking at it from an educational point of view, even though the device may go home at night our focus has got to be that education. Parents might say to us that we really want this on and there's some tough decision that have to be made there when you have a limited amount of memory space. I'm sure you guys all find- it seems before you know it, what do you mean there's no memory we just got started. Those are all issues that we look at. We feel that our district, there's not that many district around that have an augmentative communication team so we've really tried to take a real proactive approach to that.

CN What we've tried to do serving 23 school districts within one county if a kid moves across the street he may be in a new school district. So we face that, if this school district bought it and they move across the street now they belong to a different school district. Rather than dealing with it at that point what we've tried to do is to have the cooperative be more involved in purchasing the items and loaning them if the students not going to be able to procure for it- like you said as an individual because it goes back to that whole nightmare of starting over just because you move across the street or change apartment dwellings or whatever.

RC I really thing that cooperative setting is where that bank of devices needs to come from. I know in Illinois we're starting a state wide kind of movement to get state wide. You know I'll be real selfish. I'll say I'm not gonna, I don't want to send my DynaVox, Liberator, Parrot whatever it is up north. When I might need it again in six months. So you know I think that's an issue that realistically - I mean theoretically it's a great idea, but realistically I think the bases have to smaller and has to be a little bit more mobile in a smaller district community rather than a state wide kind of thing.

DH That would be more family friendly.

RC I think so

CN Even the transition from zero to three, to schoolage. When we work with that population that zero to three your dealing with an entirely different agency than you do between three and 21, and then again between 21 and adult. It's like when I get a referral on a kid who is 20 years old it's like oh man can I invite those BD people now because I need them. To not have that carryover it's like I can sit with you and we can buy this device and we can use it for one year. Then your gone and you don't have anything. If you don't have that cooperation in those transition periods I think the family can be absolutely devastated. I just can't see a way that could work.

FJ A population that we've had difficulty with in funding is the adult population. The money is not there.

CN Devices and therapy

FJ Yes, the money is not there. We have individuals with serve needs and they've got to go out and find it themselves. It's not like going to the elks club or whatever to seek funding for this cute little child. It's totally different and I'm sure you guys may have run into that sort of thing or

BC Well with the institution we don't have the funds to go out to Medicaid or to go even seek from different organizations and stuff. We can't seek monies that way and you also don't have probably the involvement. We've got so many people that we're working with and so many people that need help that person needs more of a close parent or staff person to help them seek funding that is if like they're in a group home or another type of setting other than our institution. Sometimes it does work we had individuals that have left our institution to group homes and they were able to get devices. It didn't take to much you had to go through the paper work but they were able to and that's what we encourage if you do leave. Let's work on getting some monies, some funding so you can purchase that communication device. It worked well for them. But I don't know as a whole a lot of times if the adults in the community that have disabilities if its hard you know but for these individuals it happened to worked great.

FJ I think it's opening up now with Medicaid funding communication devices.

CS Not so much focus on the medical need but on the whole person and their need cause you may not really have an intense medical problem that you need to communicate but you still need to communicate.

CN Good for you mental health.

RW Right, that's right I think it is. Debbie talking about that cultural issue one of the things that has come up in my work with the young lady of Hispanic descent was what language do we put on there. That was very interesting. She's attending school here and they speak to her in English of course at school, but the language spoken at home is Spanish. The mother- and that was quite an issue and in the end it was the mothers decision and I didn't agree with it but there was really nothing more I could do my hands were tied. That's an interesting thing her, she was looking long term about whose likely to end up being a primary caregiver for my daughter and she thought that would be her family who is Spanish speaking but what if they would not want to do it. Then it would probable be an English speaking person and that's quite and issue and I did quite a bit of research before talking with her about that and the bottom line that I was able to find out through the folks that I talked to across the country was that it should be the family decision about what language goes on there. And interesting enough she understands Spanish but expresses in English.

DH Truly bilingual

RW Yes, she is.
DH Okay I had, when we took our break a little while ago. We're going to try and wind up in the next ten minutes because I know that Francis and Rosalie need to get back to work. I kinda threw this out to you all to think about a family that you may have worked with that was very successful. Things went well verses a family that you may have had some difficulties with and if you could think about maybe pinpoint one of two differences about either the family or your interaction with them. That made one positive experience verses one as a negative experience and if everyone would like to share that information we'll probable use that as our wrap up discussion. So a family where you worked very well with the family and secondly with a family where you didn't work very well with the family and what may have been different in those two instances.

RW I think that if I look at the two families that I would like to think about. I think the fundamental difference was in their perception in that person's ability and what they were able to accept as fact and not able to accept. One family was not ready to accept the fact that their 63 year old brother would never be able to talk intelligibility. They thought he needed more speech therapy and he'd had speech therapy his whole life. That was something that they just couldn't accept and probably their were a lot of family dynamics that came into that also by saying that there was something that could be done they would have to accept responsibility of what had not been done. We tried to work through that in an informational counseling kind of way but it was a case that never came to be. So he still doesn't have a device and he still can't communicate and he's of normal intelligence fine gentlemen of 63 years of age which is a real heartbreaker. The other family that is one of the families that has produced a very successful user is a family that knows that person inside and out. They know their abilities. They know their potential and because they we're willing to accept that and work with it. They opened themselves up for all the information that could go along with this is where this individual is but this is where we can move. This is how we can get there and bottom line being that probably being an understanding of the users abilities and what the device could do for them.

CS The key word that I was thinking about was patience. One the family realized that while there was an immediate need and we all agreed yes it's immediate. This all takes time and even after you get the device it takes time to use it as we talked about it evolving. One family who really became frustrated was wanting things a lot quicker than they actually move. We kept saying well we're working towards this but patience. It's really hard to when you do have that immediate need.

RC I would say my one word would be trust. There has to be that level of trust on both sides of the table. The parents have to trust us to be out there looking for all of the devices, looking at all the opportunities of bringing the most current and up to date information we can to the table. We have to trust the parents when they say, "hey my gut says this is what goes." We must say, "okay let's do it. Let's go with our gut and let's do it." I think that level of trust between the two opens up that-- I mean you know this field is exploding and it just keeps on going and I don't know when it's going to stop. We constantly everyday have to rethink what we're doing what could be do better. You have to be able to take that back to the parent and say we've got a new idea and them not say why haven't we been doing this all long. You know there has to be that level of trust to say were bringing you the most current we can. Let's try it this way. Great, let's go for it or I think that will work because of this. So I think in my experience the trust issue has been the biggest one. That's a developing relationship which means you've gotta work with the parents and the parents have gotta be willing to work with you.

CN That was my word too. When I think of the case where we communicated the best. The best cases that I can think of in terms of relationship with a family did not end up with at least not yet with this child using a device consistently. I think there are some expectations. There are some issues in the classroom. There are some issues at home but these parents trust us and they are hanging with us. Right now their child has a device and she's not using it very well and I happened to run into that mother at a another meeting. She said, " you know right now we're working on walking and toileting. We're going to get back to that but not right now. She's communicating this way, this way, this way." That issue of trust that we can sit there and say, "yeah we know we did that" and we'll go on. We'll continue to you work with us and we'll work with you that issue of trust. Probably the case where I'm perceiving the most difficulties right now is a case where a child has a device that he is entitled to use. They done believe we're the best qualified people. They don't believe that our O.T.s are good enough. Our P.T.s aren't good enough. They won't send him to school and those sorts of things are going on. They are challenging us at every move and as much as we try to accommodate they'll turn and do something else. There's just no trust there, they won't level with us and we can't level with them and when that trust is not there and that relationship is not there things don't go well.

RC and the thought of sitting down with that, when you have all that past history or history happening. Your watching every move, thinking this will be the moment that I say the wrong thing. Being on the defensive and I can swing that around and I can see a parent being in that role real fast. So I take that feeling and say you remember that feeling because I don't want you to every be in the position where your putting a parent in that feeling. So I think that's good for us, it's not the most pleasant experience but I those take wrongs and say I want to make that none else every has this feeling in a meeting I'm in.

SE When I think about my two families the word interest or ability to give the time. Those two concepts come to my mind. One family, again this gets back to the way the device was funded. One family was funded- had the device funded by the one time only deal that the state of Illinois did. The other family was/took a real active role in getting variety club to purchase the device. So very different scenarios there. The one family who had the device bought by variety club also made frequent trips into school. So I saw them regular. They were active and participated from the word go therefore, the student (their daughter) has made significant progress. I feel their involvement has played a very large role in that progress. The other student I believe has the same ability but the parents did not have the time to make the trips into school to keep the appointment that I had made to orient them to the device, to train them in using the device. They canceled the appointments. I understand they have a work schedule and I'm not saying anything about that but I think that and that also theirs was bought for them by the funding program. That one time only funding program so there are difference there in interest level because of the differences in interest level the children have not made the same types of progress. Slower for one and quicker for the other one.

RW So that's one of the families that wasn't involved in the initial- do we want augmentative communication? What do you think of this device? They really didn't have any ownership in the conception.

SE They were written a letter- your child is going to get this. They probably had never heard of one before.

DH Barb can you think of two instances, one that might be positive verses negative or even family input as to what's put onto a board or

BC I don't know if you could talk about Bill -I know they had family involvement with him. Not so much deciding what device but getting the device.

CS That was interesting with him because we had provided him with a lower tech augmentative device. The parents been there on visit and they had observed him using it. Don't think they were all that thrilled he wasn't doing a whole lot of things programmed on there and he was using what was there. But then oh, maybe six months later I got a letter from the mother and she said, "I've read a lot and it was another device. No it was the same device and she said could we get something like this for him." At first I was a little bit aggravated because I though wasn't she paying attention when she hear before when I was showing her all this. Wasn't she watching. Doesn't she remember. I though no this is the opportunity and I've got her interest now is the time to give her the information. See, I was giving it to her when she wasn't asking for it and now that she has asked for it and I gave her the information we just went like wild fire. He had device within a year that they purchased for him that was much better than what he was using which was owned by our facility. It was her interest and whenever I was able to provide her at the time when she asked for it. Then so much more happened. So I think that kinda goes along with what Scot was saying to the family involvement.

BC It really makes a difference. I'm thinking of a situation where there there's not family involvement, but there's some staff involvement, some particular staff. They'll get out the device. They'll make it's charged. So it just depends on the interest involvement if the device is going to work or not.

DH It's almost as if staff is family in the institutionalized populations.

FJ I have worked with families that I can say are very difficulty to work with but the communication device worked in spite of that situation. It's really gratifying, I'm thinking of one situation in particular. I think the issue in this situation was honesty. Mom was late for therapy appointments. "Yes I'll be there." She might or she might not show up. "If I can't come I'll call you."- maybe she would call maybe she wouldn't. The child happened to be a wonderful candidate for the communication device very bright, very physically handicapped and mom was dedicated to the implementation of the communication device but she was not always honest with me about what was going on. "Yes we did use it at this time and yes we're going to do this." Maybe, maybe not, but like I said the situation worked in spite of all that because this child was such a good candidate, such a good candidate. I think in these situations where the communication device works so well you have that open honesty and trust with the family.

RW I think that when you evaluating you do need to impart match the device to the family also. Is the family going to be able to carry around static overlays and change those? Are they going to want to and that kind of thing? Not that should be the primary decision making factor but it should be taken into consideration because it's almost a predictor of families.

BC Or inform them what they

RW yes

FJ I think you also need to say to families when your doing an evaluation - now this is what the use of this device will entail. Would you be willing to do that or would you be able to do that? They need to be able to say honestly to you if they can't. "No I don't think in our family situation we can do that."

CN I think too, it goes back- you kinda touched on it with the institutionalized population when we deal with a number of students who have limited parents. Either individuals limited by financial need or educational needs or limited physically. We have one child whose parent is hearing impaired and so It's real hard for that parent to work and when your trying to build that trust and work with those families you really do have to consider what the family dynamics will be and what they can be capable of or who else you need to include to include as family in the institutionalized setting, or neighbors, relatives, the after school care providers, whoever else is in the picture.

SE I feel like an excellent way of getting the parents to know what's involved in having or owning a communication system is through that family support group that you were talking about earlier. What better way of knowing than by talking to other parents who have gone through it and I just think it's a wonderful program.

RC A great example of this is, we had a parent come who was going to get a device and we sat her down with another parent and teacher and had her do- take notes on it. Have her do the programming. Have her doing all that stuff and she just opened her eyes. Wow okay. And we that with our staff too, come in sit down, for speech therapist coming in that's another family member who- oh my gosh I' getting a child with an augmentative communication device. Okay, trying to prepare them and get them ready too. They can come to those support group meeting and see people at every level. The one who's over there struggling trying to figure out how do I make this thing work verses the one who's over there just going to town. Some of our groups come in and they sit down and work. Some of our groups come in and they talk about all these things that are going on. It's more important the social support is there for them that's be probably one of the best things we've done. It's cheap. It's good community and school relations. It's different perspectives brought out of school and into a central place. That's one of the best things we've done.

SE It's an ASHA seminar waiting to happen.

DH And on that note folks, I would like to formally thank everybody.

Focus Group With Related Services Personnel Working With Navajos

February 15, 1996

Sheila Stuart, Ph.D., C.C.C.
New Mexico State University

Summary Background Information

Type of Group: Focus Group with Related Service personnel who work with Desiree Mailman

Number of Persons Present and Roles: Lisa Benitez, Desiree's special education teacher for the past few years; **Marcy Nordhus**, speech language pathologist and assistive technology specialist; **Caroline Benally**, a classroom aide who works with Desiree daily at Ojo Amarillo Elementary School; **Alisha Kernagis**, a regular classroom teacher at Ojo Amarillo Elementary School; **Cheryl Calvert**, a speech language pathologist that worked with Desiree three years.

Date Conducted: 2/15/96

Where Conducted: Navaho reservation, Fruitland, New Mexico, in a module unit used as a library at Ojo Amarillo Elementary School.

Logistical Issues: The focus group moderator experienced some difficulty getting special microphones to work with video equipment. The moderator abandoned that approach and relied on the audiotape on the video camera as well as the tape recorder.

Modifications Required in Protocol: None to any extent. There was a need to remind the group to consider native language issues directly, which was not a typical focus group facilitation style.

Synthesis Statements

1. Expectations Prior to AAC Acquisition
    - Want child to talk more across settings
    - Allow child to set pace in use of AAC devices

2. Expectation after AAC Device Acquisition
    - Want child to talk to other children more
    - Progress in learning to use device with other children is not rapid
    - Peer become adjusted to presence of device in classroom settings
    - Child learns how to operate device

- Aides and other educational staff overcome fears of aac device with increased usage

3. Demands Placed on Child
    - Child learns to organize language on AAC display
    - Child learns to alternate between spelling and word selection
    - Child has dual load in academic settings: must learn content and use of device
    - AAC work load placed on child increases over time
    - Child must learn language rules to use AAC device across academic settings
    - Lengthy response time is required for child when using device

4. Training Needs
    - Classmates must be shown what demands are placed on AAC user to fully understand/respect user
    - Training must be paired with regular use of device by child
    - Providing information to peers prior to child's placement in classroom facilitates acceptance
    - Regular use of device enhances child's self-esteem
    - Adult acceptance of device facilitates acceptance by children

5. Team Issues
    - Professionals may disagree but meeting on a regular basis ensures consensus
    - Mom doesn't participate in all team meetings since child doesn't use device at home
    - Don't be fearful of making mistakes
    - All members learn new skills through collaboration

6. AAC Service Delivery
    - SLPs should provide therapy in context of natural settings
    - Presence of an aide can help facilitate successful adaptations/use of AAC device in classroom
    - Aides serve as liaison between school personnel and child and between vendors and child

7. Programming AAC Device
    - Bilingual issues change as family moves from English-speaking to bilingual environment
    - Navaho sound system differs from English-based sound system
    - School personnel may be uncertain how cultural needs of family can be accommodated using AAC device
    - Person who speaks native language of user should have responsibility of programming that language on device
    - Overlays with appropriate pictures and colors are needed
    - School personnel feel English training should be accomplished first before Navaho language

8. Decision-Making Concerns
   - Child's ability level will affect decision made regarding a specific device
   - Hands-on opportunity to use device prior to purchase is necessary

Focus Group Transcript

Desiree has been using this form of communication for about four years. Right now she had a Liberator. She had a Wolf before that.

SS Let's start out talking about expectations for augmentative and alternative. Let's talk about what kinds of things you hoped or you dreamt would happen for Desiree when she got her voice output device.

We wanted her to talk, talk, talk, that was the main thing. Express her ideas.

SS In all places?

Um huh that was our highest hope, I think. To be able to function in a third grade or fourth grade on up the classroom grades to be able to participate and learn.

SS: Okay, so talking means responding in school?

Communicating, as close as she can like the other kids at school. Not just, but to include academics and also how the other kids- out on the playground, playing with each other, getting in trouble for talking during class, expressing needs, things like that. I think that was my hope for her.

I think so when we first gave her the ROP, how quickly she went from level to level. We realized that Desiree was a very bright little girl. I know I was very excited when we got her Liberator. I also got hope that it would be so easy for her to just pick it up so fast and start telling us everything that we knew was in her mind, but I know Caroline and I talked about it. What we really needed to do was let Desiree set the pace in terms of her learning her development, her skills in using the Liberator because there's a lot to it. When your looking at academics and learning language she has those icon sequences to learn. In terms of her physical ability she had to work around that and over time we've really seen her increase her ability to work around people. I've found that it's been very important to let Desiree set the pace so that she's comfortable with the Liberator and interested in it and really sees it as a part of her. Not really something that we're trying to make her do and make her use. We're seeing wonderful things with her- the music. She's participating in music class and we have put songs in there so that other children can sings along with her. I think for me my focus is very much is on how can I use the Liberator to help her be a part of what all of the other children do in a very natural way.

SS: Yeah, I guess I really blew it here all of the sudden we jump into the questions and I we don't know who each of you are or what's your particular role in this is. Why don't we go around and say our names and say who we are.

I'm Lisa Benitez and I've been Desiree's teacher for a few years in the special education classroom.

Marcie Nordahs, I'm a speech language pathologist and in the role that I function in here I work with assistive technology working with augmentative devices.

I'm Caroline Benally I work one on one with her.

I'm Alisha Kernagis, and I'm her regular classroom teacher

I'm Cheryl Calvert I'm a speech language pathologist that works with Desiree three years.

SS: Okay, so what were you going to say?

From my point of view, in her regular classroom from what I expected Desiree, or from the Liberator was for her to be able to say hello Mrs. . I need scissors or he's bothering me or I'm done. Look at this. At first she didn't hardly use it at all and now she's using it more and more every day. So it's nice. She'll say hello, good bye. She'll say look at this. She'll show me what she's done. So she's is using it in society more and more every day.

SS: So how close would you say now her performance comes to what you dreamed of, what you hoped?

Closer, not where I want her, I want her to talk. What I really want is for her to talk to the other kids, which she does not do yet, but I can see that in the future it happening because she is getting more and more comfortable with it in the classroom. She's in a classroom with a lot of kids and she sits with a boy who's really aggressive and he really likes her. I think at times he's a little overwhelming. He means well, but she's kinds having to cope with him and so it's sometimes distracting for her to use the Liberator in talking to him whereas now she would want to talk to her partner and he is. He is kinda her care taker which has been really good for him. I think it has been really good for both of them. Don't you?

Yes

So, no it's not where I hoped it to be.

SS: Like is it 70 percent? Is it 80 percent?

I think 75 percent because there was nothing at the beginning. She's come a long way and more and more each day.

It seems like it more part of her voice now.

Yeah, and it's not a toy anymore. At the first of the year, the first three months the kids though that every time she said something they would run all 25 of them and run over and look at it touch it. It's like no big deal now. Her walker is no big deal. Her wheelchair is no big deal. She just another kid and so is the Liberator.

And this is basically the first year that she been into, she was mainstreamed a half of an hour here, half an hour there, but this is the first year that she's been included in a regular educational classroom. So that I think has been an adjustment for her and the kids. A quick adjustment.

You don't know how much following

She pushed my hands the other way the other day away and she wanted to get on that Liberator. She showed me other safety like signs like when she points to store when she wants a store award. The first time she did that I went aaaa. When she wanted to start spelling her own words, we still had to help her spell obviously but when she pushed my hands always I knew that she was really using that. That was her voice and that really excited me.

I'm finding that too, when I work with her that all of the sudden she will push me away. She knows how to do it herself and she doesn't need me to do it. When we do reading and she checks back to see if it's saying what she wants it to say and if she makes a mistake she knows know to press delete last word. So she's learning many of the other functions. Putting a period in, or make pauses so that the words don't all run i. So she's learning more and more of the functions of the Liberator.

She's using two hands. She can punch it in with this one and speak it with this one and go to tell on that one.

She figured out that if she uses even the hand that she has more trouble with she can use it to make things go faster for her. So I think for all of us she gotten along a number of years without any way to communicate except for her noises and hand gestures. I know for me I have to constantly remind myself to back off and not respond to those other gestures. To insist that she use the Liberator. It very hard not to use respond to her no matter what she does.

At the beginning of the school year, this is first year that I work with her I didn't don't what to think about that Liberator myself. I'd say oh I'm happy to help her along. You know, we're both learning I guess.

SS: how did you feel about it was it scary or ?

I'm scared to touch the computer so that just the way I felt. I felt you know if I touched something-one button then it was going to blow up. That 's exactly how I felt at the beginning of the school year.

SS How did you get over that? Or how did it come?

Well, I guess the more work that we put in I conquered it. I felt comfortable with that. I know that it not going to break anything. So then during Christmas when she sang on the Liberator. She sang a song, I felt like that was her. It touched my heart because it was her that was singing and even when we go to music you know she shows talent and it make you think that she is singing right now. Everything that she does it's her voice. That's the way I've come a long with her up to now. So

SS: So it got less frightening the more she used it and the more you associated it her and you all worked together or you all work on separate units on learning about it and putting words in. How do you handle it?

A combination, there's academic needs like Rachel will say these are the spelling words or reading words and she'll want those in. I might make suggestions about certain concepts or structures, words structures. We have a almost weekly meeting we'll ask Miss if there's something in the classroom that she see some kind of communication that she would like Desiree or thinks that Desiree needs or wants.

It's definitely evolved too because at the very beginning of the year Alisha reads stories. We thought okay we have to put all of these words in there. Oh we've got to get them all in there and then we backed off and said maybe we could get by with five words. I don't know we kinda backed off of some of that too. Pretty much Cheryl does the organization of it. We want to make sure that it in an organized fashion and looks at where they would fit- kinda of a word. What category does it fit into and then give suggestions to Carolyn and Lisa and then they talk to Desiree. Desiree kinda does the final picking so it means the most to her so she can recall it the easiest.

SS And she is usually right there when you put the words in?

She stores a lot of them now.

Yeah, she stores a lot of them.

Like I said we had to spell most of the words for her but she wants to- that pushing the hand away. Lady I want to do it.

I don't think that she at the point right now she could put it in herself.

No, because of the spelling, but if you would write it on the board. She kinda has a sequence to once she pushes the sequence that's specified. She can't read what it says but she pretty well got it memorized. I don't think, I think you would have to be there. You might have to prompt her, but she's wanting to do more and more with it.

Like with the music, she basically knows how to do it but someone Carolyn or I need to be there with her to make sure she gets exact, every little detail but she understands what we're doing with this device. How it works. How we put words in. How we can change words. In her reading there's always a few words, or names of characters that we just don't' put in the Liberator because it's always changing. She knows that she has to go out of Minspeak or spell mode and spell it. She goes back and forth between those two modes automatically now it's very exciting.

SS: What about other people's perception of her? What about her classmates and people that you see her interacting. Say you get a student teacher in.

We had that

She's just another classmate. I truly think that none of the kids think- they know that she's in a wheelchair, or actually she's usually in a walker. I'm right next to a class and the forth graders are so used to saying here comes Desiree open the door for her and she comes in and sits right down. No one says anything like oh, we've got to move or nothing. She just comes in and sits down gets to business. It's not a big deal. I did have a student teacher and I had a good student teacher luckily which is beside the point but she kinda took her in. She was just another classmate. She wasn't that different or that unique. She was but she didn't make a big issue of it. Like we have to do this for Desiree, we have to do this for Desiree.

SS: Do you think that they're maybe their sorta seeing her the same way Carol sees her as this is her voice. When it sings Dessie sings.

Right, that is her voice.

What happened- the first songs we put in were at Christmas time that was during a sing along at the Christmas program, Right? What happened with the rest of the kids when she sang?

It was different classes who participated in the Christmas program so it was our class singing these two Christmas songs. So we practiced it together within the class and then we were on the program and when it was our turn we went up to the stage area and did our part of the Christmas program.

SS: Did you have to get an extra external mike for her, or anything for her?

No we didn't they had a mike set up for all of the performers. We didn't have to do anything.

SS: How about extra- like physical work. It's heavy, you gotta pick it up. You've gotta hall it here.

I'm the one who carries it for her. It's no problem.

SS: okay

I mean it not a problem. I like Desiree a lot and I would do anything for her.

But it is looking at the future though she also got a stand to make it more visible as far as reading what's up there. She does have a wooden stand and then she's got the Liberator and then if she wants to use her walker so you know she didn't have Carolyn then there would have to be something else.

SS: If you weren't of good faith, yeah it is extra work. It plain and simple is, but obviously you saying in your mind that it is certainly worth it.

Yes, it is.

Desiree is a very mobile child if she were just confined to a wheelchair most of the time we could hook it up to the wheelchair and it would just stay that way but Desiree gets in and out of chairs herself. She moves around the room herself. She prefers using the walker and she's able to walk from one end of the school to the other. That's something that we want to encourage. Cause that why it's been so important to have Carolyn.

SS: So now, are there anything that are the down side of this that make you rip your hair our or at least be a little bit grim at times?

About the Liberator?

About the whole process of.....

I think my worst, the problem that I feel I see Desiree as a very capable child of going from third to fourth to fifth grade like every other child but the fact of the matter that she has to learn. She can't just learn what everybody else learns she has to learn extra. She has to learn the icons. She has to learn where they are. She had to learn how to punch it in. She had to learn how to adapt something so that she can get the assignment done. I think that's got to be really frustrating when you know the gap just seem to builds because while she's doing all that extra stuff the rest of the kids are on to something else. That's hard for me. - I want her to be there and I want her to be better. It's real hard to do that.

SS: So the extra learning load you see really doesn't ever go down it stays there or even expands as the functions of academics and life get more complex. If that what you are saying?

What I have also seen with reading in the beginning it was a very slow tedious process because I have to introduce the vocabulary. I have to make sure that she can read the words and so we play different flash card games until I feel comfortable that she does know the sight words. Then teach the icon sequences for the words and then we start reading it by using the Liberator. It's a long process, but what I'm finding is that it does go faster. That she's able to pick up the words faster, learn icon sequences faster, her ability to retain these sequences is amazing to me because I keep a personal dictionary where I write down all of the words that we introduce because I have to constantly refer to it. I don't remember and she just laughs. Or I'll use the Liberator and put in something that is wrong. She'll laugh and push my hands always and she'll do it right. It's fun, it is fun, but I do see the work load is increasing but yet her ability to work with the Liberator-her skills at it also are increasing. I feel as long as Desiree is comfortable and we keep that in mind and just let her set the pace. She wants to learn. She's a very motivated child and so we just let her set the pace.

SS: How about grammar and language skills and that?

She still basically unless she's got an icon sequence for a whole phrase or something. She still is basically at one word. We're working-I would say that-Wouldn't you say, one word? Overall from what I'm seeing. You can request more and she'll give you more. But there a lot of her structures that she doesn't have that she doesn't understand. She still looks at me like noun verb-she gives you that look like okay and let's push this one and that one or use that affirmation. I see that as a frustration for me. My expectations as a speech pathologist and what you want and what's real and quickest things are happening. But the fact that she's using it I really feel like it a part of her now. I think that's tremendous.

Her spontaneous language is usually is just one word responses, maybe two. But when we work with her on specific we can get longer phrases. I want, and then work on different things that she can ask for. I need, I feel, I am, we just try to work on those structures, but she'll put adjectives behind the noun. (me instead of I)

Yeah, word order, grammar there's a lot of concepts that she doesn't quite understand yet. Which is also covered in the academic acquisitions. I think my biggest regret is-- 1. I wish we would have been at this point three years ago or somebody would have been at the point when she started school or before school. That's probably my biggest regret. Just as a group how we have functioned. How I really feel comfortable that we're the best for Desiree you know. That we can be now and it's to bad that we didn't function like that three years ago, but it was more on a trial and error experience and those are my regrets.

SS: Anybody else got any of those?

No, she might be moving, that's a regret.

In the classroom the response time is a problem for me because it does take up the time.

Sometimes you have to move the Liberator around, but it's pretty normal but it is a problem because it a slow response time and sometime something is asked like spontaneous questions which take a little extra time.

SS: No, but those are the kinds of realities then that if people aren't familiar and aware they can sometime be disappointed if they're not expecting that sort of thing.

I think that I hand down?? in my class that I make that I allow extra time for so Desiree can respond to the group things like the calendar, what is the month,

February, but we have to give Desiree a little bit more time to get it into the Liberator and speak it. So I need to be patient and allow enough time so that I don't feel pressure and something else that we did that has helped in terms of acceptance. One teacher asks Dessie and I to come in and show her class how the Liberator worked and I let Deb do the demonstration. They were really amazed at how complicated it was and what she had to do in order to talk. I think that something like that is real important because I think those children have a lot more respect for her in terms of what she has to do and how very bright she is to be able to remember all of those icon sequences. She gonna have to say a simple phrase. So the school as whole has accepted Desiree.

SS: So yourselves individually, how did you get trained? Did Marcy train all of the rest of you? Did Marcy go get trained or did you all go together?

Trained through experience.

SS: Baptism by fire. Did you take the manual and the Liberator.

Well actually I think at the beginning of the year you two sat down with me. They just kinda acquainted me with the Liberator itself. I didn't learn it, but the more frequently Desiree comes the more I learn. I don't know it at all because I've got all of these other kids and I can't sit down a whole lot one on one.

SS: Do you wish you would have gotten to go off on a day workshop or something?

Definitely

I did two years ago, in the summer we did summer training which is wonderful but I think I really learned more just by doing it. I think like with a computer you can take a class, but you just have to work with it over and over to just really get comfortable with it.

SS: How about you Carolyn?

Marcy said I have a student over at the high school that had the Liberator.

Your gonna learn this

No actually that was my introduction and then we went to some workshops.

I kinda learned it basically and then ran through it with-- umh Carolyn. I think we saw a film at the very beginning. I think I went through a training and learned it and then got one. I guess we got one first and I played with it over Christmas vacation. Learned it and worked with another student on it and then introduced Cheryl to it. Then we went to a training on after the fact.

SS: Okay now, this is going to be circulated to everybody around the country. Since you've been there and done it. What kinds of things would you say to other people about decision making things, how important do you think it is, what things are the most important to be considered?

I think in a regular classroom before the child even comes into the classroom. Like the child's special education teacher might want to come in and explain to the regular education classroom- What this child is going through. What her disability is. What she's gonna brings with it. She's just like you in this way, but she has this problem. To kinds familiarize them before this child comes into the classroom because that really helped with another child that I have. I don't know if that was done with Desiree or not.

I think when I came in we talked about both of the children.

Yeah, that's right, but it seemed like it helped, because my kids are just like- she's not any different. It seems like. They're really accepting. But I think that helped when Lisa came in and kinda prepped the kids-gave them a little idea of what was going on so they wouldn't ask so many questions all the time. As far as the Liberator, I think it just took her being there a while for them to get used to it and not think it was a toy. And hear it. The more she uses it like I said the less it con?? Slower prep before this child comes into the classroom helped me.

I think it really helped her self esteem because in the beginning of the school year. I noticed that she would go into other classrooms and she did not feel comfortable but the more she used it I think it seems to help her and it makes her feel good to move her icons. Sometimes I forget and here she knows I think it really makes her feel good about herself.

SS: What would you say to other people doing a job like you? What kinds of things do you think would be important for them to think about and remember?

I guess I would tell them that it's a new experience cause I never knew that they had Liberators and tell them and I would tell how important for that child to communicate with family members, school teachers, classmates and just everybody.

I'm going to toot some horns. I think we have a great team. She got an excellent speech language pathologist that is real dedicated to getting her to using the device. The kids don't think that she's any different because the teacher doesn't think that she's any different. It think that's a big part of it. She's' got an excellent support with her special education teacher and Carolyn loves her.

I lover her, yeah.

I think the team our weekly meeting that we have really been- we had some rough waves. They're getting smoother. We're working through them. There are times when people don't agree. There are times when this isn't working. This is to hard, it's over her head and we need to go off in this direction. I think that's really necessary. Just the opportunity, if nothing else we are forced to sit down and talk about what are we doing and where are we going and what's happening. I think that we could say yeah, let's get together but we've forced ourselves to set up a time weekly. I think that's made the difference.

SS: Does mom come to those meetings?

Not usually, she has been invited for specific things.

Desiree hasn't gotten to the point yet to take it home much. She has taken it home but it's not an everyday because of the logistics of getting it on the backpack, getting it on the bus, getting it home. There are several other children in the family and it's hard. So those are future goals I think that we have.

SS: But when you make major decisions you involve mom?

Oh yeah

SS: And you involve Desiree all the time when you storing. Any words of wisdom for...

From the speech perspective, yeah, I think one the team. I think this is a lot of
Getting into the classroom I did that with another child I a had on a Liberator at a different site and it just opened up my eyes to oh wow. You know basically things that I need to look at differently in the classroom with the child and the Liberator and talk with the teacher. I haven't been able to that as much as I wanted but it does give you a different perspective than your isolated therapy room. Get her involved with the other kids with speech and language problems. I mean I had this perspective that I had keep Desiree by herself all of the time and that's the way I had it. Then somebody suggested well why don't you let's see her in another group. I'm like no, then I did it and does slow down over all for the all of these other kids so that's one draw back but in he same essence it makes her feel more comfortable. She's doing what the other kids are doing. So I think that's something else that as a speech pathologist you might want to look at.

I think last year when you were going into the classroom it helped realize what the activity was or what the rest of the kids were doing and what Desiree was doing and how can we make that mesh. I think that to me I am more and more convinced that's the only way that inclusion can work is because the teacher don't have the time to try to go through that problem solving. I think it's helped a lot to have Carolyn in there because that way it could be explained to her and then she could implement it. This is how we can adapt that activity. This is how we can adapt this activity and oh see can do that if we just did it this way. I think that has been an excellent point because that's a big way that's she been able to be included in the classroom and be a participant rather that a spectator.

Carolyn helps a lot because there are some things that I do that Desiree can't do just like the other kids. There just certain things you can't do and I'll just tell Carolyn and Carolyn knows that you just do whatever Dessie feels comfortable with. They do something and they turn it in and that's just fine. She adapts and think that if Carolyn weren't there it would be like a little different. Like Dessie would be sitting there twiddling her thumbs, but I think that if you paired her with a child it would make a big difference. But Carolyn makes all the difference in the world as far as that goes.

I think for me just having this team to work with. Last year I didn't have I was very much alone with Desiree and

You and I sit down together to do...

Mainstreaming it- We just didn't we really didn't have a lot of successes last year.

She went off by herself

She had to go off by herself because we didn't have Carolyn and she was on her own in the regular classroom with no support the way it works. There's so much flexibility- like the spelling words-right there I can just get them right down there in the Liberator Cherly can get them in for me that very same day we get the words to Alisha when Carolyn comes back she lets me know what they've been doing in the other classroom. I call Marcy on the phone at home and say help me with this. It's been a real team effort and Alisha been so flexible. We have a special project ??Des Stay Shore"" we have a special project and Des stay with me. It's flexible. There's good communication and I think that this team is just wonderful

and it's kinda perfect

A unique combination, which doesn't happen very often.

And this is what's made it a success.

SS: How about reliability and maintenance, and cost and all that stuff? How do you feel about that with the device? Let's include she had the Wolfe before know she has the Liberator. Has that been a problem for you, not a problem,...

I was in the school year I don't worry about things.

I don't see a problem with it no.

She didn't have any trouble funding it. Our director got the recommendation from the people that tested her at NMSU and we said this is what's recommended and this is what we see as professionals as the best device for her and it was purchased for her. It's very very expensive, I wonder what's going to happen if she moves to another district with that device. As far as maintenance- it was brand new within in the last couple of years it hasn't gone home a lot. So we've been maintaining it. It's been well maintained.

Well Marcy is the source for those kinds of worries.

Something's wrong and Marcy says okay I'll take care of it.

We've been fortunate we haven't had problems.

Yeah, that's the role that I play. They don't have to worry about it. If they don't know how to do something. If they've got an idea they'll come to me and if I can't figure it out. I'll call the company and find that out. So that's kinda the role I play. I would like to think, I would hope to think that has relieved them of some of that headache which does allow them to do what they really want to do and what they really need to do is teach and work with Dessie.

Even the stand, Marcy was the one who got the stand built for the Liberator because Dessie was really having trouble seeing it. I couldn't of built it but she got it made. So we've all worked together for Desiree.

SS: Let's talk about her need as far as what mom mentioned in terms of she is a Navaho and she has bilingual culture and I don't see a lot of that being incorporated into her voice output device at the moment. Is that in your plans or does it seem to hard or where do you all find yourself at in that regard?

I don't think that has been a issue until just recently. The family dynamics have changed. They're looking at moving toward family more of the grandmas and grandparents. They're maybe into that extended family situation right now. Up until this point the family was pretty much English speaking. Would you guys agree? Now the mom is looking at this because they are moving into that type of setting. They're going to be around grandparents more often.

I think to that since it been mainly at school and English- I don't know-- does she goes to Navajo?

No you took her didn't you for a while but the interest wasn't really there. Her instruction has been in English and I know Carolyn and I have talked about with Navaho there are many sounds that are not in English language so something has to be done so we sound actually make those sounds correctly. Just to plug in the letters won't do it.

You really have to play around with the phonics and the spelling.

It really hasn't been an issue since we've been looking at English only because it's been at school.

But perhaps as she older, mid school, high school age and she interacting socially more with other people within her culture and her family she may want that capability.

SS: We did hear mom say that she wished she had it. How do you feel about it?

With Desiree, just like Lisa said you know there's some words in there that you can't put in there because there's all kinds of sounds and then slashes all over the letters you know. I think it's kinda hard you know to put into the Liberator.

SS: And you think that Navaho folks are gonna forgive the fact that that's not there because they've realized that or do you think that could set up a barrier with them?

I don't think so.

SS: You think they would be accepting of the fact that that's not real flexible in that way?

You mean the Liberator?

SS: Yeah

I really don't know . I don't know if any. I couldn't say anything

SS: But we all know that it would be nicer if it did work that way.

Yeah, it would be nicer.

If there was a way to put those particular phonemes into so that you could program it. So it did sound close to Navaho.

The experience that I've had in trying to put the Navaho in i. It almost seems like it was-- We had when we did our training one of the mothers, the aunts were there and she was Navaho and she took it off into the corner and she had a lot more success putting it in than what I did even having the Navaho aunt speak the Navaho and we went through that. So it almost easier for someone speaking the language to be able to even grossly to put it into what we have now. Rather than because it like say it over, and over, and over a hundred time and then when we finally got it the person says I think it says this.

SS: What about symbols because that another thing that's some of the thing that the grandmothers told me last year that they thought the symbols should look closer to Navaho symbols.

Are you talking about the icons?

Yes

I don't, there's not, a, well I'm about as by chap. I mean the boy that they decided to pick for being an angle but the only thing that I can think of is the people that are somewhat different. Obviously their not Navaho. The mother and child it really hard to tell. I don't know. Carolyn what do you think? The pictures

They don't look like

But there's not a lot of pictures that are culturally....

SS: But if there were they would be better. Wouldn't they? It would be better if they were you think?

If would be nice to have that variety

Yeah, but like I say I won't have that voice on there for my personal use if I was using a Liberator.

yeah, yeah

But maybe if they had different overlays that you could select from.

We're not talking about major changes, we're talking a little bit of color to a little bit of pictures. That's all we're talking too really.

SS: And the grandmother told me last year that they were really concerned about the colors too cause they thought that certain colors were very important to their culture. They didn't see them well represented on the overlays.

What, the colors?

SS: Oh, like the colors. There wasn't much turquoise and they're wasn't the yellow a good yellow. It was hard for them to describe to me but what they said was that it should look more like the yarn. It should be pretty. My immediate reaction was that people who create this beautiful things like the rugs naturally would view the way that the overlay looked a lot differently than some of us who's major expression isn't in that way. But we all kinda of agree than to meet her needs in every way it would be nice to have that stuff available, right?

right, right

SS: It would also make the load heavier for her to learn, because not only is she learning one way to say something just like any bilingual.

yeah

Sure just with English she has to learn the language, learn the icon sequences everything associated with one language. Then if your going to put Navaho, then we're talking another language another set of icons to learn.

You have to weight out the consequences. What is it worth? What is the pay back?

And I think right now she had other things that I think take priority in terms of her learning. Like I said as she gets older - high school and as an adult and we look as the Liberator as something for her life that she will that will continue to grow with her then it may be something that she may really want. I would like to see her really master skills within the English language before she would try something like Navaho.

Something else that would work a lot better for Desiree is if that print out could the font could be enlarged. She has a slight vision problem and actually the print out is really for us it's not for Desiree because she can't read the fine print on it. It would be nice if that and we thought is was the cat's meow that she could even print things out and she thought that was great but know that we're doing it. It would be nice to have the font bigger even the font on screen might even help for her.

She knows that what she's puts in the Liberator is on that screen but she really tries to see it but she really can't read it the visual problems are too severe. She can't and with the print out- I've tried just enlarging it in the copy machine. When I get it big enough to where she could read it. It's still very close together and it starts to get fuzzy and that really hasn't been effective either. So those two areas are difficult with a child who also has a visual impairment.

And also the overlay as much as they've got on they've got a letter. They've got a number sometimes. They've got the icon.

She's getting better.

Boy she knows it

Remember how she would go under the tool box to do the letters.

She doesn't do that anymore.

She knows that keyboard. She's learned it.

And I think that's a little overwhelming for a lot. It was for me the first time I looked at this thing I though look at all those things on here.

I wanted to lift it too just to see the letters, it was visually pretty much.

I actually

Oh yeah, she's a lot better.

SS: Now if other teams then were making decisions about technology what things, what characteristics would you say to them be sure you consider this--like the life span of the device or the usefulness of the device. One of the major things I run into across school districts is do we buy them a more conservative device that isn't so expensive now and then if they can use that then buy them a bigger one or do what you all did. Well you sorta had done that with the Wolfe you know before hand. You made a big leap you made a big investment and said we'll just take this on and it will last her a long time. Is that the kinds of thing that people should think about the cost? Should they think about the maintenance?

Yes, I don't think that the Liberator was far beyond Desiree's capacity to make full use of it. She has the cognitive level to use it to it's maximum potential I believe. She wasn't far from meeting all of those aspects on it. The scratch pad has helped her immensely in math classes to be able to print out that information at least she could print it out instead of having to have someone else write it in for her. I don't believe that we made a leap beyond what Desiree is capable of doing. I think that device meets her needs but I think you definitely need to address her cognitive level. What do you see as their potential? What do you see how far can they get? You have to consider everything? Like with the visions, the access if she able to access it? How quickly is she able to access it? Is it going to be accepted by this child? the family? There are a lot of variable to consider. I would like to think as a team we considered most of them.

SS: Was it useful to have a hands on opportunity to try the device before and have somebody else come up and say do you think this will work?

It was useful to see a variety of them because then we could rule out the screen isn't bright enough for her. The screen she can't see. She really got off on the printing part of it I remember.

I remember as soon as she got to that Liberator her face just lit up so that told me that she wanted that device. Like Marcy said, it wasn't that big of leap because with the Rop I was making overlays that were already pretty small. They weren't meeting her needs. It wasn't enough for her so this seemed like a very logical step.

She's still limited by the device in her ability. She was really limited -we couldn't keep up with overlays you couldn't keep in the programming and we were holding her back at that time.

SS: well really appreciate you all taking your time today and most of all I want to applaud you for doing this. You can't know what it means to hear about the success after you've gone out on a limb and said I really think this will work and then go off and go uuuu. I sure hope so. And I know it works because of cooperation and the team work and the investment you've all made. Anything else that you want to say to these folks?

I think don't be afraid of trial and error. Don't be afraid of backing off. I think the more heads that's you got helps better. I think Cheryl especially has just jumped in and done and planned and worked and it is and I don't think you really felt that comfortable when you started? Did you?

You were great I think you made it. I wish you could have all the kids that I want augmentative devices for.

I just want to emphasis ??me in ??the classroom working as a team pushing an old speech pathologist like me I'm sure there others out there. When you had your training, your clinicals you had one person at a time. It's a different outlook and I think getting involved with the other people that are involved with the student. It's not this isolated I think that's real important to me.

And they have Carolyn

SS: The commitment. I hear commitment from every angle and willingness to go the extra mile. Well thanks again folks it a privilege.

Focus Group With Related Services Personnel Working With Navajos

February 16, 1996

Sheila Stuart, Ph.D., C.C.C.
New Mexico State University

Summary Background Information

Type of Group: Focus Group with Related Service personnel who work with Nate Yazzi

Number of Persons Present and Roles: **Marcy Nordhus**, speech language pathologist and assistive technology specialist; **Angela Walker**, Nate's math teacher; **Angela Harper**, Nate's regular education teacher; **Henderson Farentino**, paraprofessional; **Rena Nez**, regular education teacher

Date Conducted: 2/16/96

Where Conducted: Shiprock High School, Shiprock, New Mexico

Logistical Issues: The focus group was conducted late in the afternoon and participants seemed eager "to get it done". The focus group moderator attempted to reinforce the need to share information freely to obtain data in as efficient a manner as possible. The team did not appear to meet regularly and were not accustomed to sharing ideas. Some issues seemed to reflect differences in their perspectives.

Modifications Required in Protocol: The facilitator made careful efforts to include an equal opportunity for all members to address concepts and topics.

Synthesis Statements

1. Expectations Prior to AAC Acquisition
    - Want child to talk more across settings
    - Allow child to set pace in use of AAC devices

2. Expectation after AAC Device Acquisition
    - Want child to talk to other children more
    - Progress in learning to use device with other children is not rapid
    - Peer become adjusted to presence of device in classroom settings
    - Child learns how to operate device

- Aides and other educational staff overcome fears of AAC device with increased usage

3. Demands Placed on Child
    - Child learns to organize language on AAC display
    - Child learns to alternate between spelling and word selection
    - Child has dual load in academic settings: must learn content and use of device
    - AAC work load placed on child increases over time
    - Child must learn language rules to use AAC device across academic settings
    - Lengthy response time is required for child when using device

4. Training Needs
    - Classmates must be shown what demands are placed on AAC user to fully
    - Understand/respect user
    - Training must be paired with regular use of device by child
    - Providing information to peers prior to child's placement in classroom facilitates acceptance
    - Regular use of device enhances child's self-esteem
    - Adult acceptance of device facilitates acceptance by children

5. Team Issues
    - Professionals may disagree but meeting on a regular basis ensures consensus
    - Mom doesn't participate in all team meetings since child doesn't use device at home
    - Don't be fearful of making mistakes
    - All members learn new skills through collaboration

6. AAC Service Delivery
    - SLPs should provide therapy in context of natural settings
    - Presence of an aide can help facilitate successful adaptations/use of AAC device in classroom
    - Aides serve as liaison between school personnel and child and between vendors and child

7. Programming AAC Device
    - Bilingual issues change as family moves from English-speaking to bilingual environment
    - Navaho sound system differs from English-based sound system
    - School personnel may be uncertain how cultural needs of family can be accommodated using AAC device
    - Person who speaks native language of user should have responsibility of programming that language on device
    - Overlays with appropriate pictures and colors are needed
    - School personnel feel English training should be accomplished first before Navaho language

8. Decision-Making Concerns
   - Child's ability level will affect decision made regarding a specific device.
   - Hands-on opportunity to use device prior to purchase is necessary

Transcript

SS: This is the team that works at Shiprock High with Nathaniel, do you want to introduce yourselves?

Marcy Nordhus. I am an SLP, speech-language pathologist and I also work with the assistive technology in the district. I work with Nate with his computer training others on how to use it.

I'm Angela Walker and I teach Nate math.

SS: The purpose of this research project is to find out how this has been in terms of what you think are good about it, the things you think are difficult and generally how you might change it or information that would help other families. So, whoever wants to talk can start and it would be nice if everybody took a turn and gave their opinions and we kind of just have an open discussion.
So, anybody want to start?

Maybe I could explain a little bit about the device that Nate has. He is on a IBM compatible computer with the words plus software in it. As far as I'm concern it takes some learning training, and a definite level of maintenance to keep his device up and running. Because he acts like something on head, the switch has to be positioned correctly the device has to be turned on for him, and hooked up for him, the battery pack needs to changed, the batteries don't hold, he runs out of batteries, so there are definite concerns have hit every class that he's in. That to me has been very difficult. And I think everyone agrees.

Especially the first year. I find that something keeps popping up; maintenance and the training that it takes. We are lucky that Nate's good with his device, because we know, he knows how to use it, at several different levels.

SS: What percentage of the time would you say you are having to make time?

I don't think it's down. It's not like it has been down. I think the longest it has been down, it was a brand new computer, I think the longest its been down was two days, but it has he sometime gets into the menu and sometimes he doesn't know what he's doing and will switch it from the alphabet to the frequency letters or switch the volume off or someone else will be doing it inadvertently and I think that, and then someone has to know what they are doing in order to get it up and running again. Fara and I think was really good at that. Don't you think Fara, you got to know his device really well?

Yeah, sometimes the battery would run, we would plug it in and with the cord we had and the little box and you have to turn both sides of it down so you can see the outlets on his computer but they don't come on, you have to push them in too. That's one of the reasons, one of the problems we've been having this quarter, sometimes he'll run over it.

Cord will get in the way, the switch gets pulled apart.

I think what happened to is that a lot of this was devised for him in North Dakota and he has been away from North Dakota probably three years, so some of it he needs some fine tuning and I don't know if anybody is available to do it that fine tuning and I think that's a big thing and it's kind of lopsided now.

Yeah, that is something I have noticed I think that is the biggest downfall, the idea maybe three or four days of the five day week maybe something like that has happened. There is an instance where nobody is around to set up the computer. I heard mom say today that she didn't know how to set up the computer, when in the past she'd known, and so there is a lot of training and retraining and people forget and it changes and the switches have been replaced and the velcro has come off the switch. So that is different now and he has two different head rests, and which one is the right one for which machine. So the idea of the number of people that need to be retrained at school and home, two different environments has been a pretty big task for us right now in this first year.

I find that there is something wrong and he's not real comfortable. We try to communicate with me at the area, he tries to use his computer, and he tries to self compose sentences. He is trying to communicate with me and many times he gets frustrated his computer cannot spell in other languages. I hope one day there will be a device, a computer that will print in the other.

Right.

I find that he wants to learn a lot. He does have a good background with his language, he's comfortable.

SS: Well he obviously understands both languages very well so

Some of the sentences or phrases that he tries to types, I understand if I try to sound it out, I get what he's saying. The computer that he has now, I don't thing that it will do him any good to be a good speller. And I don't that's good. Maybe one day they will have one that will print in (?)

Good

In math class most of the time we just kept the computer plugged in so we didn't have to worry about batteries, so we really didn't have a problem there and as far as math goes most of his work, like the individualized work where he answers problems and then I have a peer professional or peer tutor write down his answers so that I have something to grade, but it worked out find for that. To me the problem would be in other classes where he would have to answer questions out loud and in English class just takes so long for him to make a sentence when you stop and think what the alternative you know it is so much better then not having a computer, that to me would be a problem because you are in a class with a limited amount of time and everyone got to answer a few questions and you ask him and it takes his computer so long, see I could see where a class like that would be a problem.

SS: Right, do you think it would of been better if he could have printed out his own answers on paper?

I'm sure for other classes it might, for math class all you've got to copy down the answers he's adding single digits and telling time. That didn't take very long. It didn't take very long for professional or peer tutor to copy down, but where if it were a paragraph he wrote for English or several sentences, I could see where that would be a lot better, a lot quicker.

And he does do that, he would print out all of his assignments. And he has printed out letters to friends, and sent letters to friends.

He has been writing letters and stories. He spelled it right

That's pretty smart.

Plus we have our new computers in the classroom the IBM compatible computers, and that won't be a problem for his teachers to play with.

It will mean an increase in independence and participation, for every class that he goes to there will be one of those computers and I think that is just lucky for us that the school has interchanged that whole concept of increasing their technology throughout the entire school, they will be a real benefit for Nate.

SS: Since you all have worked as a team, what words of advice would you give other school teams that might be taking this sort of a project? As a paraprofessional, what would you tell another paraprofessional?

In the beginning you work hard, but you also have to be patient and the thing I learn about it is it's different at home than it will be at school. But at school he really wants to learn and that's important. At home, ???????
Computers are really difficult to understand, but when you get to know them better.

SS: Does he talk to you then, and you can understand him as you get to know him? But for school it is really good because people don't know how smart he is.

It takes them a little while to understand

SS: So if I was going to start working with someone the way you did, be patient and what else?

????Treat him like a big brother. Help him with sentence correction. Tell him what's right and wrong.

SS: What a cool thing to do. What would you tell a regular education teacher?

Oh, I definitely say there is a big advantage because there have been instances when we has problems with the computer and we seen alternative to having the device and it you definitely have an advantage with the computer. There are so many more things they can do. I can ask him as his mother stated earlier, yes and no questions and I can tell the difference, but beyond that it very hard to figure out how much he understood, if he understood. The time without the computer was no communication and then they have a paraprofessionals somebody who could stand by him and stand by him. Some who knows some...

SS: So they just have to put up with this other stuff, huh?

The beginning of the year it is difficult, but after a whole it's not hard.

SS: Just all in a days work?

Yeah, you just have to shut it the right ways, and push the right buttons, and use the right program. At the beginning of the year, he used to get into it, and when he used to come back from home during the weekend and come to school and doesn't really know

SS: Just forgets?

Yeah, I don't know

SS: What about you guys, what would you tell people?

May be I would share some of the latest issues that we are all working with now, with teens. And that's the whole ideas about Nate, using his Navaho language. As explained he understand his Navaho language well, being in that environment of understand and listening receptively for the first 12 years of his life, exclusively. That's what he understands so he has a grasp the Navaho language. And issues come up when we approach the idea of Nate using the Navaho language are should we expect Nate to learn how to spell Navaho, if Nate learns to speak Navaho will he even have an audience or who will read his written output because not a lot of people know how to read Navaho language and Mrs. Nesben has been a good positive advocate of this position in out team meetings and I don't want to say what she says so maybe she can share why it's important for Nate to learn to speak Navaho and write Navaho. We're investigating getting information about different computer programs right now, but she does a good job explaining why it is important for Nate, so maybe she can do that now.

We were working...First of all let me say that Nate, someday will probably have a job, if they come up with a computer, the kind that I suggested and if he grows some more, and he might be able to work in a court herim? and help the other handicaps and use his computer to communicate. He does have a really good understanding of his Navaho. He can communicate really well in Navaho and I feel that if we don get a hold of the kind of computer I am talking about we can work with Nate and make a productive person of society and he won't know he' handicapped.

Thank you.

I think one of the things I would suggest is that you really have to keep focused really have to keep in touch with other people to see what's going on, what's happening what is working, what is not working. Our team's been probably,, we tried on a regular basis, about twice a month to me and we've tried to discuss and work through some of the problems and basically it's the logistics of getting him into the class and keeping his computer working and keeping his switches working and keeping the elevator going. I feel that Nate knows his devices and uses his device to communicate excellently that is what the focus has been in the past couple of years since he's gotten the device in North Dakota, now we redirect that and focus on academics also. He has not had a lot of academic focus, the main focus has been to use his device, and now that I think we're getting a better handle on the device and keeping it going and keeping him working and now we have to address some of the academic issues. I think communicating is a big part of it amongst ourselves, the teachers help each other. Well when I do thins, this is what I do, and I think sharing that information has helped also in out team meetings. so we're working with not just communication device, but using his communication device to help his academics and I think that will be the biggest challenge.

Beep

Especially the family, as I said before. The family has to be involved from day one or else it falls apart on the other end. Nate spends just as much time or more time at home with this device, so we can't forget that it is our responsibility too. And that is hard.

SS: Well I want to congratulate you because I know from experience and also hanging out that this is not an easy job. It takes a lot of commitment and it takes time and extra stuff out of your hide so I appreciate it and I can tell by using the device that he does rely on it and that means you all have been doing your job and I thank you. I want to thank you for your willingness to share your time with us this afternoon.

Focus Group with Vendors of AAC Devices

March 1, 1996

Sheila Hostetler, M.A., C.C.C., Moderator
Children's Hospital, St. Louis

Summary Background Information

Type of Group: Vendor Focus Group

Number of Persons Present and Roles: 3 vendors: **Teri Madak**, Speech/Language Pathologist with Prentke Romich; **Ronald Biggs,** Sales Representative with Sentient Systems; **Don Cladwell**, Sales Representative with AGS and Innocomp.

Date Conducted: 3/14/96

Where Conducted: Children's Hospital of St. Louis, a room in Spochren Tower, 3rd floor classroom

Logistical Issues: The participants were the only three vendors in the St. Louis area. Both Ron and Don traveled from Kansas City. Questionnaires were mailed and completed prior to the vendors' arrival. Questionnaires were collected on the day of the focus group meeting. Homemade chocolate chip cookies and soda/ice tea was served. All three individuals knew the focus group moderator.

Don and Teri had met several times and do not like one another. Ron met both of the other vendors that day. Don described Teri as a "dragon lady" to Ron. Don did not look at either of the other vendors during the focus group.

Observations of co-moderator (Julie Wommack): Participants seemed not to be aware of multicultural issues, e.g., one person began talking about French, Dutch, etc. Participants seemed not to have had a wide range of experiences with families, as very general observations were made about past experiences. Vendors felt that AAC was generally successful, as indicated by their inability to relate to AAC failure. Vendors generally saw their roles a being providers of devices, and seemed to place lots of responsibility on families.

Modifications Required in Protocol: None

Synthesis Statements

1. Family expectations
   - See devices as immediate fix, but is only beginning of a long journey
   - Child will communicate more effectively (immediately)
   - See devices as magic cure, but is really only a tool
   - Must overcome fear of technology

2. Positive Effects
   - Child can communicate things not anticipated by family
   - Child's personality emerges
   - Family-esteem is enhanced
   - Family works cohesively toward communication goals
   - Family shifts life focus to opportunities available to child

3. Negative Effects
   - Family must put effort into AAC for progress to occur
   - Child abandonment of device if not involved in decision making
   - Family must admit making a mistake if device is abandoned
   - Family may force use of device, resulting in other problems
   - Family may not have skills necessary to accomplish AAC goals
   - Support systems may not be in place
   - Difficulties with maintenance

4. Multicultural Issues
   - Families may have fear of computers-based systems
   - Device demonstrations may be intimidating to families
   - Some systems accommodate bilingual users
   - Pride of family may negate willingness to use AAC system that's English-based
   - Families require training regarding use of AAC system in the "work of the user"
   - Families may prefer different icons on AAC systems

5. Family Roles and Changes
   - Siblings may have to assume responsibilities for AAC use with younger users
   - Grandparents may have to assume AAC roles and support parents
   - Siblings may desire to use device for different activities than preferred by user
   - Relationships with child will change when child begins to communicate
   - Family may choose crude or impolite language for child's use in some contexts
   - Family use of time must change to accommodate AAC usage
   - Families may have difficulty knowing how to prioritize time for AAC use at home
   - AAC device usage become natural part of family routines
   - Stress is minimal, but becomes pronounced if family fears devices
   - Stress is reduced if device is incorporated into routines appropriately

- Stress is high at first because many elements must "fit together" in child's environment
- Positive or negative influences related to child's choices in dealing with AAC demands
- Communication

6. Community Issues
   - Persons in community must be trained to use AAC with child
   - Persons will express curiosity regarding devices
   - Families can do things in community not possible in past
   - Family and child will learn natural consequences of AAC usage

7. Family concerns about AAC
   - Range of devices available
   - Families should contact vendors or consumers with experience
   - Families require vendor support, demonstrations, and rental options prior to purchase
   - Cost
   - Maintenance
   - families question whether they make good decisions
   - Families should assume role of expert

8. Roles of Family Members in Decision-Making
   - Families should be involved in decision-making early on
   - Provide information regarding child's communication skills across settings
   - Support use of device
   - Must recognize that devices don't last indefinitely
   - Must recognize that devices may not be ready for immediate use
   - Since AAC system changes, ongoing commitment and supports needed overtime
   - Recognize technological obsolescence will affect availability of parts
   - Recognize that devices will need to be replaced to maintain communication efficiency

9. Working with Professionals
   - Families must recognize that professionals don't have all the answers; AAC is a new field
   - Families must put energy into AAC implementation
   - Families must get education regarding AAC
   - Families must be patient
   - Families and professionals must clearly communicate expectations
   - Family priorities will be different from those of professionals
   - Families may need longer trial period with AAC device prior to purchase
   - Professionals should help alleviate fears and concerns regarding devices and routine changes
   - Families must assume responsibility for following through with AAC

recommendations

- Professionals must clearly communicate their roles in the AAC process
- Families must display confidence in themselves and be willing to make mistakes

Transcript

S: Thoughts of families and children who own AAC devices, those who have not received them. I'll just go ahead and pose a couple more questions that relate to this. Do you think that their goals or expectations change after they receive them the devices and in what way? So Terry I'll go ahead start with you. You want to tell me what you think the expectations are for families with children who want devices.

T: A lot a times they see the device as a fixer. That it's going to be an immediate repair for all of the issues that they've had to that point. I think that they underestimate the amount of long term effort that a device takes. That the procuring of the device appears to be their primary gusto; they normally see the long term that the initial purchase of the system. It's really just the beginning of the journey for communication.

S: Okay Ron

R: I seem to agree with that. I think that initially when they start pursuing getting the device that they feel that once they get the device then the child is going to be able to communicate more effectively. It going to increase their learning capabilities. Which I think that is one of the reason why they get the device, but you still have to do a lot of things before you reach that point. I don't believe that the parents always realize that up front. hey say okay we've got it. It's a long road to get the device to start with and then once you get the device in effect then your just starting a second go round of the journey because you have to put the effort and the time to make the device effective for the child once they receive it.

S: Don do you have anything?

D: No disagreement, whatsoever. Took all of the words right out of my mouth. They see a device as.. let's see you called it a fixer, but it's because we have so many technological things that are advancing so rapidly. We're able to do so many more things then we used to be able to do because of various microchips and that sort of thing. So that most families have been watching to much TV in my opinion, without reading the reality behind it they see this as an automatic magic cure. It isn't a magic cure. It's a tool. It's the same as a carpenter having a saw or hammer. You need the tools but the carpenter still has to do the job.

S: In what ways if any, do you think an AAC device positively affects families? Can you think of any Don that you see positive effects with families?

D: Very often a family finds out that first of all they have to overcome some technaphobia.

They're afraid of the technology. Often not always, it's like you have to wear thick glasses and a white lab coat and run around and say odd things and a million pens in you pocket. That way you would be qualified to program this device. I think one of the positive things is overcoming that and finding out that it's no more complicated actually as far as the customizing of it then using a microwave oven for the most part. In that the other positive thing is that then this child sometimes is able to communicate and say things that people didn't expect them to say. So your finding out that there's an individual inside there not just a child but a person. I can remember a couple of families where the siblings had never really had any real interaction with one of the children who then got a device and they started having conversations. Now they were slow conversations but they at least could get some idea of what that boy was saying. So there's two positive things that I can think of.

S: Okay, Ron

R: I agree with that. One of the big positives is when a person gets their communication device and then they master it where they can start communicating with it. You start seeing a personality come out. Especially with our product a lot of times when you program them initially when they are younger your kinda having to set responses to come back. As the individual grows with the device then they have the capabilities to start creating their own messages and start sending out more of what their personality is in responses. So that's a real positive there and then again it gives the child an opportunity to interact and they probably never had before. Many times you'll see the child can interact well with the parent and the immediate family members when they're around them at such great lengths by making certain responses and gestures to get what they want. But then when they go to school or in a different setting they really need a communication device that can communicate effectively in that setting.

S: Terry

T: I'm probably going to agree with everything you both said. I think that the total esteem of the family is elevated. I think that they're working as a cohesive unit to improve the communication of the family. I think they have a tendency to focus in on what they are saying, opportunities that are available, shift some of their focus in life to more of the opportunities that may be available. I see them becoming more independent in what they are actually doing in the environment. It allows them to reach out to other activities and even other opportunities for that individual. They are seeing that technology that communication part allowing them to reach into computer access, into environmental control, and seeing possibilities for that individual grow.

S: Okay, just going now talk about some of the negatives are. Ron I'll hit you first. You want to think what could some of the negatives that might impact the family?

R: I think that one of the first things that comes to mind is ..... we touched on this a little bit earlier. That individuals have to understand that once you go through the long process of getting the device that you then have to put forth the effort to make the device effective for the individual. We mentioned customizing. You need to take the device and customize it for the individual. Keep the individuals focus and work with them on a daily bases because I've come back and talked to families after a little while and their expectations are not being met. When you get into a conversation with them and ask them, what are you doing? What can we do to help out? and things like that. They're really not putting forth the effort and that's really an important factor that you have to be willing to put in the time. I think that everyone sees the difference in certain families. You can leave them and come back in a couple of weeks and just be amazed by the progress they have made. In another instance, you can come back in a couple of weeks and maybe there was not any progress made than on the other hand maybe there was not the effort put forth. That just one of the things that people need to keep in mind.

S: Don, Can you think of any negative feelings families have had?

D: Rather than reiterate what has already been said. Which is pretty much. Some negatives, yeah I can think of a couple of new ones. One is sometimes the child doesn't want to use it period. You can't make anybody do anything. I'm talking even an adult maybe they don't want to use it. But nobody really bothered to check with them, or there was not way to be sure of the response. That person thought this would be a wonderful thing because it's new. It's this toy. It's something new in my life. Then they find out that they're going to have to work to use it, or at least work to learn how to use it and then they don't want to do it. They go back to the same grunts and groans, or gestures, or whatever they were using in the past. That's a negative. Then the family of course feels like they have a couple of different responses. Either we made a mistake (which most people don't want to admit) or we're going to have to force this person to use it. Which is sometimes necessary. Then you come into all kinds of different problems. Really there's no broad statement that's going to cover them because its individual by individual. So there's a negative that you didn't touch on.

S: Do you have anything to add to that Terry about negatives or do you feel like it's been covered?

T: I think that families are often times poorly equipped with the skills that they need to be able to accomplish these goals. I think that other negatives occur when the support network is not accomplishing the things that the family interprets as being in their position. I also think that the service and the care of the device itself often times causes problems that they are not equipped to work with. I've seen systems that have for some reason been broken down and never followed through and repaired. Several issues - they don't seem to have the support network to solve some of those problems sometimes and they become so instrumental in those things and they give up.

S: Our focus needs to also talk about multicultural issues. I guess first I would like to know have you had much experience in dealing with families from other cultures other than European American. That would be like Hispanic, Asian, African American, just curious about how you people have had much experience with other cultures? So Ron do you want to tell us a little about what your experience has been?

R: I really have had limited experience with other cultures. I haven't really had to deal with the language barrier yet, I know in other parts of the country people are having to deal with that a lot more than I have. Just from some of the other cultures- they may not be as well adapted to some of the things in our environment. Ours is a computer based program and you get a lot of fear of the computer initially. There's this fear that I don't have a computer. I don't know how to work a computer. Therefore I can't learn that, but I have had a lot of positive results from that. Spending the time training and educating them and showing them that this is not as difficult as it looks. When I'm sitting there hitting the buttons and making the pages change and when somebody is just looking at that it can be a little bit intimidating. I haven't been in the business so long that I forgot that I was a little imitated when I first seen that product as well. I think that if you spend time with them, everyone is able to learn if they're willing to put forth the effort it takes.

S: Terry what's your experience with people of other cultures?

T: We have... I think part of PRC being worldwide we have dealt with multiple languages in our devices. One of the greatest pluses I think of digitized is that we have the ability in several of our systems for users to be bilingual. So that they can communicate in their home language in their home environment, and then come to an educational experience or workshop and speak in another primary language. So I think we have seen the technology bend to provide that various.... our sister company over in England does a lot of work with different languages and finds that many of those people are very well equipped to take on some of the computer age more than some of the individuals here. I've had a couple of individuals come to trainings who were unable to speak English. There's no question that it was a challenge to try to teach some of the things and provide them with a level of support that we felt was necessary.

S: Don do you want to say anything about cultures?

D: The digital output is fine. That's about the only... at this point the real way without having a specific device in a specific language with those specific programs built in. Which here we don't have, you can get them but there are rather expensive. So that the German and the Dutch and French all have different.... they have similar sets and then their differences are pronounced. The gutturals are in the back of the throat and that sort of a thing. Well it's true, you don't really roll your R so that's .. if you don't go digital that's.... your really kind of. Most of the are proud enough that they won't bend to you. So we've generally gone with a digital output device. Which no matter how good it is. It is still limiting in what can be said. You can't just type in a bunch of letters and have it come out being what you want it to be if somebody didn't put it in beforehand. So I haven't had to deal with more than one Dutch man, one German lady and several Spanish folks. It's one of those if a person really wants it again they'll accept. It depends. There's so many variables.

T: There's a lot of companies over in Europe that are very active. I think that's how we got our foot hold in the foreign languages.

D: There's a Swiss company

T: So this is not something new to Europe and Asia.

D: But they do have, the Swiss company that I'm thinking of which is where you guys got your things started our out being a Swiss device but they had specific language. They've got that set for France. That set for Spain.

T: We have that in ours.

D: I can't remember what the guys name is who developed all that stuff.

S: Have any of you had requests for like some of the devices to be in like African American dialect or ......Terry your nodding.

T: Yeah, because we hit so hard on vocabulary. We spend a lot of time training the importance of that. We're always asked how you customize it or do we? What's our job do we teach English or do we teach in their dialect? So we spend a lot of time teaching the importance of allowing that person to communicate in their own world. How we can make modifications to the system to allow for that. We also have icons that reflect various multicultural individuals.

R: I haven't had much experience with that request yet, just a couple of times. I've had more questions based on the icons. Could we make some changes to the icons for them primarily is what it's been.

D: I haven't had any

S: No?, We're going to talk a little bit about roles that family members assume and orientation of the home environment. Do you think that having an AAC device would affect roles that family members have? Do you think that it changes them or affects them at all?

T: I see a lot of siblings taking on responsibilities with the younger sibling with their device. I think going back to what the gentleman have said about going back to peoples fear of technology. I think the older siblings have a tendency to jump in. Kids are very technological today and there are very excited about the technology and do a very good job of mentoring. I think we're seeing a lot more of that kind of issues. We see grandparents taking on some extra roles: getting the training, learning how to use the system in order to provide some support. I think to the parents.

S: Anyone else?

R: Certainly, I think that there are a lot of changes that take place and I think the more change that the families are willing to make the more successful they can be with the device. The sibling getting involved. That's an excellent example. I've found with our product that they........ you have to keep them from almost taking over the device. There's different things that they like to do on there when they see it. It does allow them to get involved and communicate and have some interaction that they haven't had in the past.

S: Don, do you think that AAC devices affect relationships of family members?

D: As a fore mentioned, yes.

S: So you think the sibling would be

D: No, not necessarily, it could be the parents too. Again you have children for example who are.... you maybe always thought this person haven't you ever heard that where the mother said I know exactly what he's thinking all of the time. Well, then they get a device and it like where did you hear that? How did you know that? So that's of course on the cognitive level of the person. Or when the person is finally able to say no I don't, I'm tired of eating whatever it is. There are a number of times that happens. So that certainly has an affect on people you begin to find out that there is an individual in there. That's probably the biggest affect that I've know. Another thing is that I had one little fellow that his parents programmed all kinds of terrible things for him to say to his brothers. (really ugly things) He spent two weeks saying those ugly things. Then that was enough. He got that out of his system because all of the other kids were able to say those things and he never was able to do that. So for him he got a big giggle out of saying your ugly and your mother dresses you funny and things like that. So of them were pretty vile actually. But that's one change. Another thing is that when a person is able to not be polite all of the time that another one. Often handicapped people are always polite. Please get out of my way. Please do this. Please do that. Thank you very much. When what they really want to say is get out of my way you idiot. They're not able to do that and sometimes putting those things in allows the individuality of that person to come out. Maybe they'll say please sometimes and sometimes they're not going to say please. So I don't know whether that answered your question or not but there you go.

S: Anyone else have any comments on that....... Another thing we talk about is demands placed on time so adding an AAC device could also add some time constraints to the family as well. Ron do you want to talk about that?

R: Sure, I think that it is going to change how they are going to have to focus their time. Initially there is going to be a big commitment to the device. You need to set it up appropriately for the individual. You need to work with the child to make sure they understand the effect of the device. When they make certain responses they immediately expect something to happen. It's bringing in a communication device as one way to change your time but it not unlike a lot of other family issues. If you bring in different items. If you happen to bring a pet into the house that's going to change how you focus your time. Somebody is going to have to be responsible for feeding and cleaning and things like that. So while it going to change the time, I don't believe it's a detriment in any way. I think you just have to prioritize what you want to accomplish and make the appropriate adjustments.

S: Terry do you have any comments

T: I think that the time is overwhelming to these individuals. They see this as such a huge responsibility on top of the responsibilities that they have. I find that we make comments like just use it at home. Then they see them needing to run around with this device in their hands for their whole evening. They aren't sure how to use the time they need to spend with the system. I think that if they could be provided with better information as to: you don't say to run around with it all of the time, there's certain key times when the system could be made available, and this is what we want to accomplish during that time. I think we could take some of the overwhelmingness of the time commitment away from them and focus it more in things that they can actually accomplish.

D: I don't find it to be that way at all

S: You haven't?

D: Generally it's again it kinda like more like what Ron says. For the most part these people are spending tons of time on this child anyway . You know feeding, turning, setting up wheelchairs and so forth. So what I've found most of the time is that it's just incorporated into everything else. It not, the original, the initial when they first get it yes there is quite a bit of time spent but after a while it sort of becomes part of the routine. It's not an extra demand it's just part of what we do for this particular person or what you do with this particular person. Seems to me, so.

S: We're going to talk a little bit about stress now. My favorite topic. Don do you think that having an AAC device would affect levels of stress that families are having? Do you think that it would be an added stress?

D: Oh it can be, but I don't think it's more of an added stress. Again, just stated than much of anything else. Everything is so stress anymore. The added stress sometimes if it's not working properly or if they have hit the wrong button and cleared all of the data or whatever or gotten into some place that they can't seem to get out of. Then they would be stressed out. Generally, yes it may add some stress, but I don't think it's significant. It can be significant if the person remains afraid of the device. Then it can be significant. So again it's dependent upon the family.

S: Okay anyone else, Ron

R: Well I again think it depends on the individual. Hopefully after a certain period of time it would reduce stress. You could start accomplishing some things with the device. Like Don said there's a lot of stress for the many activities but I believe if you incorporate it appropriately and learn the device it will reduce the stress level.

T: think there is going to be a level when that occurs. I think that adding to what these people are handling certainly is for a certain time period going to increase it. They're also usually incorporating people that they're working with having to make things fit together. Communication is such a critical component to so many things in life. I think it has a tendency to assume a stress of it own because you what it to succeed so critically you want it to work there are so many elements to make it successful. It's so much further beyond just whether a device turns on that day. There are just a lot of factors involved there that's going to make it work or not. I think those have a tendency to overwhelm people. I think that it needs to be a concept of trying to get that handle and get it appropriate.

S: Okay, Ron do you think it would affect the relationships that family members have with others in the community having an AAC device? Do you really think it does affect their relationship with others?

R: I think it could and it depends on how the family handles that. It could have a very positive effect by allowing the individual who is using the device to start communicating some of their thoughts and personalities. On the other hand it could also have a negative effect. If they didn't want to use the device at times because they felt embarrassed or some of the other feelings. So, again a lot of these issues could go both ways. I really believe that it come down to how that chooses to handle them.

T: I think that we need to put an effort into teaching people in the environment how to interact with individuals who use AAC systems. Some of use have grown up in a very segregated kind of experience where individuals who have special needs were people who were put away. When you see individual who are different you have a tendency to cross the street. So I think that we need to help people learn how to communicate with this person. See that as being valuable. A lot of times if we can get someone to talk to an individual who has a system. They don't know what to say. They have a tendency to say things like: does it talk? make it say something, and that's across the board of professionals, as well as lay people. It's just an understanding of what this took allows this individual to do. I think that from that standpoint you may see some affect in the community. You may also see that affect greater because this may be an individual who has not gotten out in the community quite a bit. When they go to McDonald's the child is the child and or adult may be put back in one of the booths and someone goes up to order for them. Now suddenly we have a system and we want that individual to order for them self and how are the people at McDonald's going to respond to that. Learning how to ask questions. So be may someone who is being shoved into the environment more. So the contact is greater and your probably going to see more responses than you might have.

S: You just segued into my next question which involves going to restaurants. So wanting to know if it would affect families ability to take their child into the community to restaurants, or other social or recreational activities? How do you think an AAC device would affect that? Don

D: If it allows the person to better express themselves, then that's you answer. I find that most people in restaurants in most towns go out of their way to be as helpful as they can to anyone who's got anything wrong with them. An augmentative device is just as neat. What is that? Even old ladies are like going like, what is that? You know and then the person says something. It's pretty obvious what they are doing. So restaurants and Wal-Marts you see a lot of people with augmentative devices. After a while, once somebody....... The initial thing isn't shock, it's curiosity. After that it's like it just part of..... like someone with a hearing aid. Okay, they're using that- go on. So it affects them in that they can go out.

S: So you feel it affects them pretty positive?

D: Yes, I do

R: And it shouldn't, that should be one of the support mechanism of the family to encourage them. If they want too go out and if they want to go places. They want to go to restaurants. Their family should encourage them to do so because know they are going to be able to communicate. That's one of the positive affects of the device. It gives you some freedom to go out and do some things that they weren't able to do in the past.

T: My experiences are relating back to something Don said earlier. I had a parent who took a child to McDonald's. They always ordered her a vanilla or chocolate shake. That was her choice. She drank about a sip or two but that's what they liked. So when they took this child to McDonald's for the first time, she ordered a strawberry shake. The mother said, "no, we don't like strawberry." She remembered me saying that we need to learn natural consequences and you need to go through with that. Sothey went ahead and got the strawberry shake and sat down and the child drained the strawberry shake. By going out and letting her be independent she learned things about her child. Her likes and dislikes that she thought she knew very well.

S: Next we going to talk about kinda concerns and I'm wanting to know what the greatest concerns that you've encountered in working with families during AAC decision making. What is it that they are really concerned about when your trying to decide on if they should have a device or what device? Ron what do you think?

R: I think one of the biggest concerns is being able to find out what type of devices are out there. A lot of the areas they may be exposed to just a couple of the devices. They may think they are appropriate or not appropriate which is not really important but I think they always wonder what does this device do. A lot of times they see if on a piece of literature or a catalog and they never get the opportunity to physically touch it and evaluate it. So I think that one of the biggest issues is to be able to see the different types of devices and even work with them with the individual whose going to ultimately be using it and help make their decision making process a little bit easier.

S: So maybe just seeing the variety, getting to see all of them

R: Seeing a variety of them and then narrowing down the decision. From that point I believe they should contact a representative or someone who has a device, has some experience with a device because no one is going to know the capabilities of the device as well as someone who uses it on a day to day bases. A lot of people who are out there could show the device but they may or may not know what the capabilities of that device are. So it's becoming......... As there's more products in the market, and as there's different ways to approach the communication needs of the individuals. It's going to be more and more important for companies to support the products appropriately and the individuals not to hesitate to call on the companies and have a demonstration or possibility a rental period to see, if this is an appropriate device. I think that's just the biggest issue that I've heard out there. Well, I've heard of this device. Do you know what it is? Even if it's not my company. Do you know what it is? Do you know what it does? They are kinda limited on the information.

S: Don do you have any comments?

D: The two concerns that I have come across most are price. Which is always a big concern and ease of programming and maintenance that sort of thing. How long does the battery last? How do I this or that or the other with the device? Those seem to be the two major concerns because usually by the time I've gotten there anyway. There's a therapist involved and they have narrowed things down pretty much to one or two devices. They have already seen one or they have seen this one or they haven't seen one but the main things come down to: how hard is it to use? How hard is it for me to use? How much does it cost? How much does it cost if I have to buy this accessory or that accessory? Those seem the at that point the few major concerns that I run into. Can uncle Frank use it on his computer? I actually had a person ask me if they could use an augmentative device in their home business. Let us know if you can?

T: A new product line.

S: Terry

T: I think the underlying concern that I hear from most families is that: are we making a good decision? Is this going to make a difference? We've bought other things before and they haven't worked out. What is this going to do for us? What can we expect? Just being concerned if they're making another leap of faith so to speak. Are we going in the right direction? What's going to come out next year? Should we wait until next year until something else comes on the market? I think that's a central as well as a family's' concern.

S: Okay, Terry can you describe what you think the roles of family members are during the AAC decision making process?

T: They are the experts with the individual. They live with them. I'm hoping or would like to see their role be paramount. They need a strong understanding of what kind of commitment. So they need to be involved from the beginning as far as gathering case history information, as to the family member and things they've seen and observed what kind of environment they live in. Getting a survey of: what does this person their day, week like? What kind of system do you perceive they need? What is the rest of their system like? Do they sign? Do they use manual systems? Do they gesture? How is this piece going to fit into their total communication system? So I think that they can provide a tremendous amount of feedback as to this individual on a regular bases as well as the history. Often times when you do an evaluation you may get their best day you may get their worst day and as others have said it starts out being this really cool toy that is something new and exciting. So I think that they can provide us with a lot of information about this person and also provide us information as to whether the environmental support will be what it needs to be for the system to succeed.

S: Anybody else?

R: I would just agree with that. The family needs to be involved because they are going to have to help support the device. They can provide the input and help direct a purchasing decision when it gets to that point. I think the more they are involved throughout the process the better off it is after they receive the device.

D: Quite often they are the one that's doing the pushing for the device in the first place. So they are in that part of the decision making process because they are the one saying this child needs something.

S: Don, can you think of anything that... like.... for AAC devices tend not to be considered by family members? Things that they're not thinking about?

D: I think we have pretty much covered a lot of that actually, earlier. We've talked about maintenance. We've talked about price they think about. The continuing effort and the continuing...... as with a wheelchair you have to have people adjust wheelchairs but because it's electronic people don't have to ever adjust anything or change anything. It's etched in stone.

S: Maintenance is something that you don't think they think about.

D: Well, sure all of them run on batteries. Those batteries don't last for ever I don't care whose they are. They go down eventually and or the charger burns out. That happens too, regardless of whose charger it is eventually it's going to burn out. It's going to die. Or plugging it in during a lighting storm some people do things like that. They can't understand why it doesn't work anymore. Why the whole back is melted. Well, gee these things happen. Actually I made that up. But that type of thing the common what we call common sense which isn't terribly common relating to electronic devices .

S: They think they'll last forever and that they should.

D: But they've replaced four TVs in the last five years or something. So.... but this is supposed to last forever. Well it can always be fixed but you still have to send it in. We're not going to know it needs to be fixed if you don't tell us it needs to be fixed. Things like that..... just maintenance things. Those are the only things that I can come up with at this time.

S: Can you think of anything else?

R: We may have touched on it, but just the effort it's going to take to get it going. You mean when I get this it not already set up for my child? I don't think that they realize that a lot of times even if your there early on and you say you need to customize this for the individual. Then they think that when it comes occasionally it's already set up. It's not.

T: I would agree with everything that they've said. Probably the third piece and Don kinda hit on this is the fact that these system do grow. They're out grown. You do have to move on. So you don't buy a system for life the technology does change. Funders do purchase second and third systems just like they do wheelchairs. That you can't... you don't want to go in and think this is a one time chance you've gotta buy it all. We need to be matching the technology to the individuals needs. Not where we think their needs will be in 10, 20 years because the device won't be there in 10, 20 years. The electronics...... it just outgrown to quickly. I think the service issues: the reality of shipping the device, boxing the device up. Some of those issues are things that they don't think about. The ongoing support is the main issue.

D: Actually one of the things........ That I was thinking of was not that you couldn't use this device for that person forever. It was that if you get to a place where chips can not be replaced because they are not manufactured anymore. It's not that the device is not perfectly adequate or couldn't be made to be perfectly adequate. It's that those parts simply don't exist anymore or the price of this particular capacitor has sky rocked for some unknown reason. Usually it's chips. That chip has not been made anymore and hasn't been made for five years. Therefore, if that goes out there is nothing that we can do for you. We can not replace the chip. Those things people don't think about. Which is what I getting at with- we've replaced four TVs you know but they are all using some different electronics. The devices themselves generally most everybody's' device that I'm aware of grows pretty much with the individual. There may come a time when you may want to try something else but they pretty much grown or regress with them too depending. The electronic parts of them are not always manufactured and that would be a need for replacement at that point should the device break down or get hit by lightening or run over by a truck.

T: I think my comment was more that the technology is there to make communication and language easier, more possible, access has improved so greatly from when I started into this field that the device they are using may work but the options that the t and the overall energy that they are having to expend to communicate can be reduced significantly allowing them to communicate more freely you have a piece of technology is upgraded and some of the options available to them that were simply not even dreamed of thirty years go. So I think technology moving ahead and the means of that individual changing such that a new device may need to be purchased not that they old one can't be repaired and rejuvenate but it's just not the most efficient way for them to communicate anymore.

S: Okay, What advice could you offer family members on how to better work with professionals when trying to identify AAC devices for children. Terry I'll let you start with that one.

T: Thank you, I think trying to be open and realizing that this is such a new field still, we're all learning, making assumptions that because they're professional they know this field well. I think has often got many of my families into problems. Getting a can do team work, we'll work together to solve these issues, We'll do the best we can, I think that the expectation is always that the professional knows all of the answers. And then they're very disappointed when the professional isn't perfect. Whether that be a physician, speech language pathologist, occupational therapist. I think we really need to get an understanding that we're going to put a hundred and fifty percent effort in and we'll do the best we can but we don't know all that there is to know about AAC. It's still a field that develops very quickly and the things that we used to teach and the things that we used to help and support people with we're looking back and wondering why we did that. We're a pendulum swinging kind of profession from the stand point of how do we do this, how can we best meet the needs, so I think a little of understand of that.

R: I think they should realize how much effort they are going to have to put into this and it's ultimately going to be their responsibility. A lot of times I've seen individuals depend on other professionals to find the funding source or recommend them the perfect device that going to do everything that they want it to do. They need to take the time to educate themselves on the devices. They need to take the time to educate themselves on the process of getting the funding and realize up front that it's probably going to be a long journey to get this accomplished. It's not going to happen in two or three weeks. The more they can understand about the process the easier it would be for them and the less stressful it would be for them in going through the process so I would just encourage them to before they jump in and say I want this device next week to realize that this a long process, educate yourself as much as possible and then be patient and in the long run when you make the ultimate decision I think you'll have a better opportunity to get the device that appropriate for your situation.

S: Do you have any advice for families working with professionals, Don?

D: It not always possible to find somebody that you can work well with and those are just the human relationship problems that people have. Be polite when you need to be polite; be obnoxious when you need to be obnoxious. knowing the differences and knowing when is when is not always the easy thing to know. Generally most of the professionals I've run across really try and as long as the parents try and everybody trying and everybody knows that everybody is trying it will work out all right. The other things are just personal issues that happen so be nice mostly and be obnoxious when you need to be. But do expect that whoever your working with get together with them and find out what they expect and let them know what you expect because nobody's a mind reader. If you don't work together you won't have a common goal and then your working sometimes across purposes.

S: Do you think that the values and beliefs of families are different from your and if so how did these differences affect what happened when decision were being made about AAC devices. Can anybody think of a time when they felt that the family values and belief systems were very different from your own. Kinda a culturally specific question or it could be.

T: I think the families who have priorities that may be different than what I might have as a priority for my family. Not that one was right or wrong I think that when you are passionate this field you see this as being such an important issues when I ,...... I remember working for the health department years ago and wondering if whether the money needed to be spent to teach the child to say I'm hungry or that the money should be spent to put food on their table and I think it's setting of priorities their family that often times come back shaking my head. That's probably the only thing that I've run into.

R: That's a difficult question because we all have our own priorities and ways that we believe and things that we want to do and you see a lot of instances where in the back of your mind your thinking one thing and they 're making comments and going a direction that maybe you would not want to but it's still at least in my position it's my responsibility to represent the product and let them make the ultimate decision on that. Now decisions that they make, driving home I may say well I sure won't of did it that way but I don't have to be responsible and answer for the decision because I'm not making the decision, but I would say it happens fairly often just because everybody has different priorities and beliefs and different things.

S: What changes are needed in AAC decision making processes to make it easier to work with families? Can anyone think of something that could be done to make it easier to work with the family?

T: I think basically many of the things that we've already talked about more involvement in the decision making process a better understanding of what's involved when the system arrives, a better understand of what it's going to do. How it fits into their current system. I think a lot of it is education. Being able to spend time with an individual who uses a system to get a feeling of what it's like and you know. I sat many times and talked to families they sit there and yeah, yeah we can do this and when it comes down it's like wow we didn't expect this. Some of that is really hard. It's like trying to tell someone what it's like to give birth. you can tell when that first hits, I'm sure you guys appreciate that but you just can't read it in a book. But I think that's true of these systems. Maybe a longer opportunity to try the systems before a decision is made to really get a feel of what the investment and what the outcome is going to be like.

S: Think of a time when you worked very well with a family and a time when you didn't. Can you describe what was different for these families and for you? Don?

D: The difference between the two families that I'm thinking of is the mother was schizophrenic and later was placed in a mental institution. That was a very difficult family to work with because she was yelling and screaming and then very nice and then yelling and screaming and I was like aaaaa. Later she was taken away by little guys in white coats but I didn't know that at the time. That probable the weirdest family that I've worked with. The child was reasonable normal as far as I could tell. The mother was angry at god because her child had this problem and she apparently never got over or something. Maybe she' over it now I don't know but the other family, most of the families I work with are pretty decent, I haven't' had any real problems occasionally I have people- nervousness your talking bout stress and that fear of getting all this done which everybody has touched on. The main differences are whether the people are terrified of the device or of the change in their family or whatever. That usually is what brings on any problems and once you get into it. It's like oh well it isn't that hard then things go better. The only worse time, well there was another one

S: Not a another schizophrenic

D: NO, she was just weird and they left their kid a home, a residential center and called me from Arizona saying he needed a new charger or something for his device but they were in Arizona and he was so place else. I 'm sure we all have stories like that

S: I'm ready to hear someone else'. Ron do you have any contrasting stories of when you've worked well with a family and when it didn't go so well?

R: Well, I worked well it was the individual had a pretty good understanding of communication devices ass well. The child had a device prior to one that they got from our company and so it was pretty smooth sailing. So I was just responsible for supporting the device. They had a really strong understanding of what they needed and it really couldn't have been any easier. I believe that family had done a lot of research prior to getting their first device and put a lot of effort in it the child functioned very well with the he product. Those make it easier. Kinda the contrast of that is were I was working with a family and they just wanted a device to appear they didn't really want to do anything as far as assisting in the funding, even though the funding was there, it was just a matter of making a small effort to get it taken care of. I talked to them on the phone and the response was I'm really stressed out today you'll have to get back to me and while it's our responsibility to be professional and go forward and support them If I had driven three hours to be in a particular area and we had agreed to take care of it. It may be another month before I'm back in the area and then there were some delays because the individual didn't want to take care of it at that time and then obviously as it turned out of course it was our fault that there was the delay. So it just...I'm just a firm believer that it goes back to families taking the responsibility following through I think almost all the professional people I work with in the period they really care about the families, they care about helping them and if the families will step forward and take on some of the responsibility it will certainly make their and our lives a lot easier.

S: Terry

T: I think it deals with our expectations of our role and I think that pretty much what you were talking bout Most of my families are wonderful people and they are constantly thanking Prentke Romich for going the extra mile and very positive. Although everybody has those families. But I had a lady who lived two blocks from me and she basically wanted me to live with her with the device. And she got really hostile when I would not come over in the evenings and it was real hard for me to explain my role and what I could do a lot of time I find we're in the role of teaching more AAC than the system itself and so I think it for people to understand what our specific role it so that misunderstanding don't occur.

S: Is there anything else about the subject that I haven't asked you about that anyone would like to talk about because is your chance?

D: Don I can think of anything I think we've just about covered everything.

R: I think we've covered a lot nothing really comes to mind.

T: I think one of the comments that I think that is important is that families need to have the confidence to try. Don't get so worried about making the decision, getting in there you need to go ahead and jump in it's one of those jump in and you swim and you do the best you can. One of the worst things I think about parenthood is that hind side is always 20/20. Your gonna make mistakes your gonna make wrong turns and just go in and accept the fact that your going to make mistakes but in making the effort and going forward with the concept you've made a good decision in that standpoint and that down the road your going to get the chance to make another decision. This is not a life time sentence that your setting yourself up for it's something that you jump in and you do the best that you can and then you jump again.

Focus Group with Related Services Personnel

March 14, 1996

Sheila Hostetler, M.A., C.C.C., Moderator
Children's Hospital, St. Louis

Summary Background Information

Type of Group: Related Services Personnel

Number of Persons Present and Roles: **Angela Reed**, physical therapist and former employee at Children's Hospital; currently providing home health therapy and one of her clients just received an Alpha Talker; **Laura Hohnstrater**, occupational therapist at Children's Hospital who conducts AAC assessments and provides treatment to children 0 to 21 years of age; **Belinda Pankoff**, speech pathologist employed at the Delta Gamma Center for Visually Impaired who works with children birth to threes who are blind or visually impaired; **Phyllis Crafton**, employee at Gateway Michael School (St. Louis City Schools); works with children three through 21 years and has had many AAC experiences over time; **Barbara Swanson**, Special School District speech/language pathologist in St. Louis County who conducts augmentative and alternative communication evaluations; **Cheryl Anderson-Miller**, speech language pathologist who is an independent contractor with facilities serving individuals with developmental disabilities and mental retardation; makes number of recommendations for individuals for use with augmentative systems and former employee at Children's Hospital; **Vicki Frerker**, speech pathologist employed at New Horizons and self-employed; works mainly with children zero to three years who are developmentally delayed population; has referred many children for augmentative evaluations.

On the whole these individuals did not know one another or may have met occasionally. Angela, Laura, and the focus group moderator have worked together at one time. Other participants had been met by the moderator during evaluations conducted at Children's Hospital or other professional activities.

Impressions: Few disagreements occurred during the focus group. Consensus was reached on many issues. The participants stressed that AAC success was up to clients and their motivation level. There was a perspective from someone from a group home setting. it was felt that socioeconomic status was much more relevant than the cultural group of the individual. Family concerns were represented as cost. All participants liked the idea of parent support groups. More volunteers are needed to start one. Participants advocated for community education.

Synthesis Statements

1. Family Expectations
   - Have same communication skills as others
   - Increase opportunities & interactions with community
   - Not all families want AAC

2. Changing Expectations
   - Greater communication competence seen after delivery of AAC device
   - Expectations may be lowered
   - Frustrations can occur given programming and maintenance demands
   - Time constraints may inhibit use of AAC systems by direct care staff
   - Parents of younger children have greater hope that speech will be developed
   - Hope of families related to disability age of onset

3. Positive Effects of Device
   - User communicates experiences , thus becoming a "source of pride"
   - Families enjoy users saying "I love you"
   - Families like "memories" of child talking about past experiences
   - Enable play with siblings and interactions in family activities
   - Dynamic voice interactions more positive experience than static systems

4. Negative Effects of Devices
   - Added burden, "one more thing to do"
   - Stigma of appearing different
   - Family may feel stress as function of having to train professionals to use device
   - Stress may be related to "working out bugs" of device

5. Family Responsibilities
   - Identify broad range of vocabulary options and teach child pragmatic rules regarding use
   - Interpreter role for communication utterances; this changes with increasing child communication proficiency

6. Environmental Changes
   - Battery charging routines
   - Ensuring availability of space or routines
   - Consistency in routines
   - Attitudes of family may affect decisions made about environment
   - User attitudes will affect environmental changes
   - Abuse or improper maintenance is issue in some settings

7. Changes in Family Routines

- Must commit time to learning to use and maintaining device and teach child
- Frees need for 1 on 1 with child
- Complexity of device linked to time demands

8. Cultural Considerations
    - Goal to communicate supersedes cultural differences
    - Economic level has greater influence than race
    - African American wants Standard English programmed into device
    - Therapist don't consider slang/dialect during programming
    - Family and user interests more important than ethnicity

9. AAC and Community
    - People in community display mixed responses to and abilities to interact with AAC users
    - Nature of interaction required with user affects perceptions and willingness (causal versus time-constraint)
    - Need for education of all community
    - Family must deal with frustration inherent in trying out devices in communication settings
    - May use at home but not in community
    - Can draw unfavorable attention
    - Family comfort with device affects community usage
    - User motivation affect community usage
    - Degree of physical ability affect community usage
    - Degree of dependence on other affect community usage
    - User responsibility for device will affect acceptance
    - Appropriate monitoring systems necessary
    - Initiation of conversations by user in community seen favorably by families

10. Families and AAC Decision-Making
    - Cost is first concern expressed by families
    - Parental perception of presence of and acceptance of disability affect involvement
    - Support training is priority
    - Use of AAC system is greater when family is trained at every step of implementation
    - Families trust professionals in the public schools
    - Families provide information regarding daily communication needs
    - Compromises must be made with regard to cost
    - Families don't consider that devices have limitations; discourse style will be different with user
    - Must consider time commitment required to learn use now and over time
    - Must consider lifespan of device
    - Must consider versatility of language across settings

- Must consider hidden costs
- Families should note questions for presentation to professionals
- Should use 800#s to access information
- Should seek out knowledgeable AAC professionals
- Should cooperate with professionals in designing systems
- May expect professionals to know everything
- Users should be involved; results in increased learning and greater acceptance of AAC devices
- Waiting or lag time is frustrating
- Ability to participate linked to SES

11. Professionals and AAC Decision-Making
    - Respect family priorities
    - Educate family regarding use of AAC in community
    - Value family members as team participants
    - Use of questionnaires helps communicate value of family members
    - Communicate role of family in decision-making
    - Make loaner devices available after evaluations
    - Evaluation process may have unfair elements: optimum devices may not be feasible due to funding
    - Awareness that technology options are increasing in midst of decreasing funding availability
    - Training provided should focus on integration of device into home and community

12. Use of support groups
    - Support groups should be developed to disseminate manageable parcels of information
    - Groups should be developed prior to delivery of devices

Transcript

AR My name is Angela Reed. I'm a physical therapist. I used to work here at Children's and I worked with the rehab kids a lot, so I'm experiences with the talkers that they used at that level. Now, I'm doing home health therapy and one of my kidos just got an Alpha Talker. So I'm working with mom, you know kinda back and forth here with Shelia. We're trying to get that going.

LH I'm Laura Hohnstrater. I'm an occupational therapy at Children's with Shelia. We do assessments and treatment for kids, well zero to 21.

BP My name is Belinda Pankoff. I'm a speech pathologist. I work at the Delta Gamma Center. I work with children birth to three that are blind or visually impaired. Several of my kids have been here for augmentative evaluation.

PC I'm Phyllis Crafton. I work at the Gateway Michael's Schools. I work with children from three through 21. Through the years I've had many students on augmentative communication devices.

BS I'm Barbara Swanson. I work at special school district in St. Louis County. I do augmentative evaluations. We send kids back and forth to Children's all the time.

CM I'm Cheryl Anderson-Miller. I'm a speech language pathologist. I guess I would just say I am a sole contractor. I contract will facilities with individuals with developmental disabilities and mental retardation and make some number of recommendations for individuals for use with augmentative systems and used to work here at Children's with Shelia.

VP I'm Vicki Parker and I'm also a speech pathologist. I work at New Horizons mainly although I'm self employed. Work mainly now with the zero to three developmentally delayed population. I used to work up to age five and I referred a lot of children here also for augmentative evaluations, usually on the pre-training aspect for myself.

SH: Okay, What do you perceive as the goals or expectations to be for families of children who want the AAC devices but who have not yet received them? Barb I'll go ahead and let you start.

BS Well, one of the primary goals that I think a lot of parents have is that their child will be like all of the other children and they'll have the same communication skills That one that is a major goal, not necessarily realistic but one that needs to be addressed before the equipment is obtained.

PC I'll agree sort of. I think that they want their child to be fluent so that their not a frustrated with being unable to communicate. I'll agree with the part that I think that many peoples expectations are really false. That they think all of the sudden once they get the device that the child will be able to communicate like a child with speech and it's not going to happen.

Exactly

VH I think that one of the realistic goal for families is that this device may help enhance their child's opportunities. I think that might be very accurate.

AR And also just the matter of being able to communicate with people outside of the family because family members may know just from facial expressions and that kind of thing, but it could really open up more for them in the community.

PC I think also, one thing that we've found is that sometimes the parents don't want it. They don't think that they need it because they communicate fine with their child and they don't realize that other people don't do it quite as well as they do.

SH: Do you think that their goals or expectations change after they have received their AAC device? Belinda?

BP I think so. I have known parents who were unsure of their expectations were and then they've really seen their child take off with an augmentative device. So they have been pleasantly surprised. The child really had more communication skills than they thought initially.

SH Anyone else seen anything?

BS Or vice versa, sometimes they can tune them down to the skills of their child too and have really more realistic expectations. I think that once you get that device that's kinda a leveling point.

AR I think there can be a lot of frustration just in terms of expectations and then even if the child doesn't have the motor component to really use that device. I think there can be a lot of frustration and at that point. Once they have the device things have been built up.

CA Well, I think sometimes when they get the system too. It's frustrating for everybody involved because my feeling is lots of times I think they're surprised at how much maintenance it takes to keep the system going. Just to keep it functioning day to day. Keeping it current. Once the user gets a little bit more proficient you can start adding vocabulary and stuff. I think they're kinda surprised with the fact of backed expectations. I think that a lot of people just expect it to come programmed with all this wonderful stuff in it and it's just going to do all these wonderful things.

BS The child or the user is going to it, and do it all.

CA Automatically, once they see the system they realize that's not the case.

LH And for the child to be motivated to do it. I think a lot of times, like you were saying Phyllis the families are able to know what the child needs just based on facial expressions or whatever. That child's needs may be met quite easily by familiar people. If their met, then a lot of children don't see the need to communicate. For us, as professionals and to help the families find things to motivate the child when they can't communicate those needs in other ways. It's a real challenge.

CA Well, I see that where work the families that I work with are direct care staff as opposed to like a mother or a father, an uncle or aunt. Lots of times it's easier for direct care staff to communicate with them without the system. So the system is reinforced and isn't used. So I don't know if that kinda goes into expectations once the system is there, but I kinda see that it's kinda **ten handed** sometimes for the care staff or the people assisting them. It's easier to just go ahead on facial expression as opposed to taking the time to encourage the child or the user to use it.

SH: Okay, In what ways if any do you think a device positively affects families? Vicki do you want....

VF Well, I think, I've thought of several. One is that the child begins to communicate things that he's never done before there's enormous pride. I think if they do bring the device into the community given a positive situation where the teller has time they will get a lot of positive feedback from unfamiliar persons.

SH: Okay, anyone else?

CA I've had families member say to me that one of the things that meant the most to them was when their child could tell them they loved. They had a way to say I love you mommy or I love you daddy and how important that was.

BS It's almost like they become a functioning member of the family. I remember one little girl. She was maybe seven or so and it was the very first Christmas that she could talk about the prior Christmas with her device. She had the language and her mother said we now have the memories. That was really important to the family.

LH I think of it in terms of sibling relationships too. It allows sibling to be able to be able to communicate and maybe play a little bit more with the children too. For them to be a more active participant in the family just in the day to day things.

BP That's what I've seen too. It's a real positive thing for families to give the sibling a way of interacting.

SH: Okay

CM I know that this is only supposed to focus on devices with voice output but when I compare trying to get users to use static system like picture boards and object boards. You don't get the same amount of interaction as you do with a voice output system. I think that having a voice output system you know especially if it's a user that been having picture board around the house or object boards around the house. All at once there's a more dynamic interaction there. I think that's a really positive experience too. You all at once get a voice to go with that action.

SH:: Okay, now we're going to switch and talk about negative impact. Do you think there are any negative impacts of AAC devices. Phyllis do you want to start with that one?

PC I guess, maybe it's just one more thing to have to do. One more thing to carry. One more thing to have to charge. One more thing to have to make sure it's working and then time calling the vendor to find out why it's not. So is some ways, it's taking up more time.

BS There's the cost factor.

VF And it's possible even a stigma factor. I do not agree with that, but I do know some people feel their child who looks perfectly normal until they carry a device and then all of the sudden their not the same as everybody.

BP I think that when the programming and maintenance falls on the family's lap it is very stressful. Especially for families that live in rural areas. I know one family in particular, the mother felt like it was her responsibility to train the speech pathologist because in this rural area this particular professional had no experience with an augmentative device. I think that can be very stressful for families especially in families where the child has other disabilities and there's a lot of things that need to be taken care of.

SH: Okay, anyone else? Then we're going to talk about family member and roles now. Do you think AAC devices would affect roles that family members must assume? Laura do want ...

LH I think so. I can think of an example of a child that we saw here a Children's. The family was wonderful about putting all kinds of fun comments and things like that in his device, but he for the first time he was able to communicate things like that, but the family really needed to intervene he had a lot of fun things. He would say kinda off color comments to his brother and joking with friends and things like that but when your in some place like the grocery store or something you know it's not an appropriate time to say some of the fun things that the family was finding that they really needed say to say no that's not an appropriate thing to say here. We were very glad that they were putting different things on his device because he was never able to say fun things like that. Things that might be funny to tell his brother, but they did have to kinda set some limits for him. Let him know some things some social appropriateness kind of roles that they had to do in terms of what he should be communicating out loud and where.

SH: Anybody else noticed changes in family roles?

BP I've noticed that the parents shift from being the interpreter for the other children. The child with the device then can start communicating on their own and that child doesn't always need someone else to interpret for them. I think that's been nice for families.

CA Did you say rules or roles?

SH: Roles

CA Oh, I thought you said rules, I'm sorry.

SH: Let's talk a little bit about organizing the home environment. Do you think that having an AAC device would affect the organization of their home environment? Cheryl do you to talk about that one?

CA Well, I can kinda look at it from two different perspectives in terms of like a home, home. You definitely have to organize a place to store it. A place to store all of the things that go along with it, like if you have a desk matte or table mount as well as a wheelchair mount. If it's someone who ambulates in a wheelchair or if it's someone who ambulates in a wheelchair plus a walker, then you have to start thinking about how are you going to have this accessible to the person no matter where they are. Also in term of just legalistics. Where are you going to plug it in to charge it at night? Where are you going to keep if you've got a toddler who pulls everything down, especially if you looking at a seven or eight thousand dollar device. So yes, I think that probably in terms of changing the environment and how the environment is set up. Probably a lot of families do cause I know that a lot of families when they hear about how expensive these thing are their like- We can't take responsibility for that. What if it gets broken? Who's going to pay for it? So I think there is probably a lot of changes made in the home environment.

VF I think just keeping track of when you plug it in and being sure that you have the right number of hours. You don't over charge it, depending on the device that also can be.

BS Although the changing of the environment shouldn't be expensive. It's just finding a place and keeping that place almost like making it holy. So that the place for itself. As you say, the calendar for charging or whatever it takes.

You got to go into a routine

In some households that's very difficult

CA It's very difficult in the situation where I work where it's caregivers as opposed to parents. You've got different people with them every single night and trying to keep that environment consistent. I think the key your hitting is consistency within the environment.

BS Absolutely

CA Some of the situations. It's really

BS A lot of it is just the attitude of the family. If it's in a home and if the attitude of the family is positive and they can see there's good effects coming from it nothing is to much of a problem. There are other family's where - oh my god, we can't even find a plug . It's just a major problem. So I think a lot of the questions that we were asked and are being asked today hinge on just the attitude of the family.

AR I think also something to keep in mind are the families to keep in mind are the families where there's nursing coming in to assist. That you also have to take into account their attitudes about- this is one more thing that I have to contend with, one more thing that I have to or it can be very positive yes, I can finally communicate with the child. You will probably have ever range of attitude coming through that house so you have to be prepared for everybody.

BS Plus, how important that system is to the user. I have some users, who it would be fine with them if it just stayed on the table. They'll use it if it's in front of them, but I have other ones that just they make it their issue in life to make sure that they have their communication system from the time they get up to the time until the time they go bed. It's just depends upon how important it is to them as well.

PC There's some situations that you can't even send it home because you won't see it again or if it comes again it won't be in usable condition or whatever. So

VF Like if it has to go a school bus I imagine

PC Well,

BS Or if siblings get a hold of it

PC There's just not respect for it. It goes home and then if the child is not coming to school consistently, then it's not charged. Every time it comes in, it's lost all of memory and it dead, dead, dead. So there's-- that the extreme, but it happens.

SH: Okay, we touched a little bit about the one on time. Do you think would having an AAC device would affect demands placed on families times. Laurie your nodding?

LH I'm just thinking of all the different aspects. There's just time, in term of ..... we've talked about the up keep of the device in just the day to day maintenance but also the time of how invested the family is in terms of learning how to use the device. Learning how to help their child use the device and progress with it. If they have to go to any extra places for therapy to get more training, there is that part of time that they need to devote.

PC But, there's a flip side. There's the time saver because if you have somebody who's independent then they can do a lot of their schoolwork, homework on it. So all of the sudden when you have to have an adult, or sibling, or somebody sitting and working with the child while they were doing their homework. They can do it independently and that can save a lot of time. The everyday time.

BS Another time aspect is your going from an individual who was not communicating. That takes no time whatsoever to an individual who is communicating and it takes time. A lot more time and that's probably a big factor, especially initially.

AR That varies too with how easy it is for the patient to access that device. It may take two minutes for one person to say one thing. So that could be a big issue.

CA I think another factor is the device chosen. Like a Liberator is going to be a lot more time consuming in terms of maintenance and in terms of learning how to use it. etc.. then say an Alpha Talker. I think that makes a big difference too, in terms as what is chosen for that individual or what best suits that individuals needs in terms of how much time.

BP I think also the users level of development I see with really young children that parents put in a huge time commitment. In getting their child accustomed to using the device and having it in a place in the home where they'll use it. So just the parents getting accustomed to using. I think early on it's a very big commitment especially with the very young population.

CA Do you see that...,.. I might of miss understood your comment. Do you see that parents of young users are willing to give more time that say parents of 15 or 16 year olds?

BP Well, I don't know. I only work with birth to three kids so I don't see the older kids. The parents of really young kids put in a huge time commitment with the device because they 're home with their child.

BS Let me speak from somebody who works from about one year to twenty one years of age. The only difference that I can really see in parents is that the fact that the parents of the really young children still have that hope in the back of their mind that their child is going to talk. Parents of the older children don't have that hope and again it varies from family to family the amount of investment time and so forth. I think they're real similar, the gamete.

AR I think that also probably depends on something where the child was born not being able to communicate verses a car accident at 16. Where there's probably still some hope that we're going to see some recovery and some progress.

SH: Okay, let's talk a little bit about levels of stress within homes. Do we think that AAC device would affect the levels of stress which parents and families are currently having? Having the device gonna be an additional stressor or is it going to lessen it? Who would want to start with this one? Vicki?

VF I think it would just vary as we've talked about families. In some families this would great. This would be an improvement. In other families it's one more thing to carry, one more burden. I think that would be an individual family situation.

AR I think it may also be a time. Like maybe at first, it's a little bit high stressed since you're trying to work out all of the bugs. Trying to figure out why it turned off for no reason and all that. Once they understand what's going on it may decrease the stress because there's better communication.

SH: Okay, I'm going to start talking a little bit now about multicultural issues because probably you can share with me if you've had other groups. Probably in our community we're mainly EuroAmerican and African American and I guess I'm wondering have you found any differences or are there any things you've noticed in particular working with African American families as opposed to EuroAmerican? I know there is a lot of discussion right now about vocabulary and selecting devices because you know that don't really have devices that speak in black dialect for instance, but you can customize it if you have the digitized speech. I would just like to hear your experiences in working perhaps with African American families if you noted any differences or the same, kinda what you think. Angela go ahead.

AR I don't think that I've really seen a difference between I think that basically everybody has the same goal to communicate and especially early on the needs are pretty much the same kinds of things. So I don't really think that I've seen a difference in terms of.

BS I've never been asked by an African American family to put any special vocabulary in. I'm not aware of any, of that ever happening or any doing anything special, doing anything any different than what we would do for normally for any child.

VF I think the only area that I've experienced some differences. Not so much as African American, but SES and that is I've had a couple of very sad stories where the mother couldn't come to the training session. I was going to drive her to the session. The next time she didn't come. A child became ill, canceled the appointment because he was sick and then didn't reschedule an appointment. I lose the children at three, so I wasn't able to follow up and continue what happened next. So I don't know, I think it might be an economic difference more important for some families than perhaps race.

PC I'll agree with that and I think it's not as much as the language that goes into the machine as the respect that they have for it or the need that they have for it. Probably for me with in dialect and what not- I have a teacher who's African American and she was very specific that she wanted anything that was programmed into the device to be programmed in standard English. She's African American and she speaks standard English. I don't know what she speaks at home but in the school and interacting in her professional environment. So with it --maybe somebody who at an intellectual level where they would be code switching it would become more necessary to have the dialect in it. Maybe more frustrating to me with this teacher was that she was also very insistent that things be done in complete sentences. I think when we're using a Liberator or in those days the Light Talker with some kind of head pointer or head stick that sometimes it's far more functional to use telegraphic speech. A lot of people are hung up on full sentences, so that would be more of a language and programming problem that I would face. I don't know in particular why this African American person stands out expect that she was the one who was very insistent that we have full sentences and that they be in standard English.

SH: Cheryl do you have any thoughts?

CA No , this is one area that I really haven't worked with families in terms of the input that they wanted in terms of different race.

PC I now have one boy and this is not as much African American or dialect as teenager and slang. He would, when he started building sentences on his own, using words. He put in something like "you be girl" and said it to his best friend. While it was one of the first things he said and one of the most touching things. It's not anything that I would have thought to program in, but he was able to use the words that were in there, put them together and then say something in his--- that was appropriate to a teenager.

LH I guess we see in our evaluations.... we see such a wide variety of people. We'll see from the boot hill that aren't very well educated and maybe illiterate. We see people from the boot hill that very well educated and very well literate. We such a wide variety of people and again like I said before what we try to do the most is to find what's motivating to that particular person and that particular family. If their interests are rap music like I know the child that we saw of Angela's verses the girl who we saw last week who really liked country music. Now, the ethnicity wasn't much of a difference as just what that individuals interest were and that family's interest were.

AR I think we have to be careful not to get to get caught up in trying to just classify just based on race. I would rather just look at individuals and what their needs are.

SH: Okay, is that all? We're going to talk a little bit about the community now and how do you think AAC devices would affect the relationship that family members have with others, particularly within the community. Community being- restaurants, churches, malls you know where ever. Laura I'll let you go ahead and start that one.

LH I don't know. I think having a child use the device in the community is such a true test for them. Especially in a child who has problems with access. I just think about some of the experiences we've had and how important it is for people in the community to be patient and not to try and speak for that child. For the parents to try not to speak for that child. I think that it is real difficult for people in the community to know how to respond sometimes. When I think of when I in the community. I know what a Liberator is if somebody has it on a wheelchair because that's what I do for a living, but I could probably count the number of times I've seen someone in the community outside of a therapy session on one hand using a device. I think the community doesn't know what they are and I'm hoping or sometimes surprised at how much people have to say when they do say it. I was at the mall a couple of weeks ago and their two ladies that had Cerebral Palsy. They were both in power wheelchairs and both had Liberators. They both were physically very severely involved, but of course I'm standing one behind them in the pretzel line and can see that they've got a word strategy. They're going um. They .... I just remember the look on the mans face like "wow". This person is smart. She can order her own pretzel. It was a really positive response. Whereas, on the other hand I've taken........ they were able to select their things quite quickly, but we've taken kids on outings before maybe it takes a little bit longer for the child to access their device and to get their responses. I've seen some people try and answer it for them and give them choices when just really need a little bit of extra time to help them communicate. So I've kinda seen it on both ends.

AR I think it depends on who you encounter in the community as to what the response is going to because they could be open minded and very "oh that's great" or they could be "pu" you know. It can really pull them back further is someone who has already got something against someone in a wheelchair. So I think it depends on who you come up against.

PC I also depends on what your doing because one of my students- we take her out socially and we took her out to a swim meet actually. So we had plenty of time and we were just kinda sitting there. She had her Liberator. We were talking back and forth and then all of the sudden all kinds of people who were just sitting there came over and they were interested in knowing what it was about and that's real different than when you standing in line behind that person. You've in a hurry and you want to get your hamburgers and they're going and not getting anywhere.

SH: Anybody else had experiences in the community?

VF Well, I think having community based instruction is very, very positive for all of us to try to teach shop keepers and possibility help develop a sensitivity. If there is a long line, maybe we could just wait once in a while or sometimes we'll forewarn the McDonald's that were planning to come and try to pick a not to busy to time to go. I think as instructors we can be sensitive to the long line and the wait because that does I can see how that would irritate, but were not a representative. Our individual child is not a representative for a whole population. He is just one person. He has a right to wait in line and order just like anyone else.

AR I think it would be great if there could be more community education just about what these things are and if somehow that could come of all of this that would be wonderful. I think a lot of people would be responsive in the community and more supportive if they knew - what is this thing that cost six thousand dollars?

AC A lot of people don't understand. When I try to explain to people in the community or and again I'm going to go back to care takers. A lot of the caretakers that I work with (I don't know if I should call them care takers), primary care staff. When I try to explain to them that we're ordering such and such for someone. There're just lost. They have no idea what we're talking about and even after and I can't really explain it to them until after we actually have the system right there. They don't understand and they don't understand how it works or even the purpose of it sometimes. So I think community education is a good idea.

PC I had a situation where I worked with one of my students over the summer. What we would do is-- we would do-- it was all community training. Trying to take this Liberator and get it out of the classroom and out of the home and into the community. So we did things like go to the science center. Here you are your in the science center. There's kids all over the place, adults all over the place. Everybody is all over the place. We would look at something and then we would want to talk about it because she was accessing it with a head pointer or a single switch. It took a long time and it was not real functional and you know we tried several places like that. Then other reality of it is- that is doesn't work and you have to send it back. So there were a lot of frustrations in trying to get this out into the community, because here I thought we had the most ideal situations. We were going to gas stations, libraries, and all the places that you've wished you could take your students. It takes a long time to get a whole class to a field trip. This was more natural because it was only one of her and some of us, but people around would kinda look. Like I said before, depending upon what the setting was they would either range from curious to let's move on.

BS I have lots of former students who are now adults with their devices. They'll call me at any little quirk, any problems like getting into the movies at the Galleria or what have you. Those are probably former students of mine that you saw at the pretzel stand. I could probably tell you who they are because they are the mall queens. They will persevere and make phone calls and their very independent getting information, going places and so forth. The only place they've ever truly feel and they use the term "shut out" of was one of our own local agencies that supposedly provide adaptations for people with disabilities. So they wanted me to intervene. To explain who they were and that people like them would be calling. So I think that's really interesting.

SH: We've been kinda talking about the community, so let's get back to the family's perception. What do we think would affect the family's ability to take their child into the community like to eat at restaurants, or other social or recreational activities? Do you think having that AAC device is going to make them more likely or less likely or will it be pending on the individual?

BS Oh, I can speak to that. I have a real classic family. In fact, it's the little girl that I talked about before, even if I call up I can hear her talking in the background. I have met this family out for dinner. One time we were up at the Wisconsin Dells and we were out spending the entire day. The child who's not a child any more. She's in her twenties. They never brought her system with them. You would think that there would be that pressure that I was going to be there, that they would bring the system with her. They kept telling me that they forgot, they forgot, they forgot. I truly believe it goes back to the fact that even though she's in a wheelchair and she's strapped in and has problems with head control, that it's the device that the feel makes her appear different. I don't know if it's the voice that coming out, if this big box in front of her or the fact that something like that would draw attention to her and you could tell that she's was disappointed that it wasn't with.

LH I had a child that I've seen in the past who's mother we could not get her to get into the community. She was so proud of her child for having this device and using it successfully because he was quite physically disabled and he would directly access and he could do it very well. Looking at him most of the people who you see day to day just would not think that he had hardly anything to say. He was a very sharp child and he would say a lot of things. He did talent shows with his brothers home school group. He there's just so many things that just opened so many new avenues for them to do in the community. It was really nice for this family and mom was just very proud because she was a teacher and she knew that her child was bright. She knew that he could do a lot of different things. It was almost like she wanted to prove to everybody else- yes, my child may look like this. He may look like he doesn't have a lot to say when actually he really did.

AR I think it varies on the individual family and their whole approach and feeling about the child. I know the one patient in particular that we share common. She will be everywhere with it. There will be no qualms with it whatsoever. Who cares who's waiting in line. She would use that. I think that will really vary with the individual, but I think for her it would open up a range of activities.

BP I think if the family's are comfortable with the device it will go into the community.

LH This mom was very comfortable. She was very invested and had a lot of training in it and had devoted a lot of time.

CA I think it also comes back to something that Barb said earlier too and that 's how motivated the user is. If the user is seeing that it's really changing their life. They are not able to physically get it and take it with them but they have someone do it, then they're probably going to insist that it be done. That it be put on their chair or it be provided for them in the community. So I think some of that user motivation that you were talking about earlier has to do with whether or it goes into the community or not too.

BS So much depends upon even the physical abilities of the user. Can they actually do it? Then there's no choice. They basically do it but if you rely on others you know it doesn't matter how old you are if your still dependent then your still looked on as a young child and mom and dad continue to make those decisions.

LH That's what I was wondering about Barb, is did the girl that your talking about did she -- was it okay, was it acceptable to her that the device was not taken into the community.

BS No she wanted the device, especially when she saw me and you know because we sit there and we talk the entire time. She turned to mom and dad and gave them a look and protested, but it was already to late. They had already made the decision for her. Now it's been a couple of years and maybe things have changed. I don't know. I was really disappointed.

VF I think that the devices are going to get better and better. I think the latest Liberator allows you to program using scanning. If you can use scanning to program and if a client can program his own messages as the child gets older and older. I think that the devices are going to get better and better. I feel as if we're just at almost the very beginning, not quite. You can go back a few years but I think that just as the devices get better and better. I think we'll see more people using them and able to use them well. If you can say Happy St. Patrick's Day it's not going to be useful all year, but right now it would be really neat to program that in, but if you have to have mom do it or the teacher does it then you've cut down the number of people that are going to be able to do that.

PC One of the things that I work on with my students is to give them the responsibility of making sure that the device is charged. We do it with the wheelchair or whatever. We know you can't physically get up and plug this in but it's your responsibility when you get home to make sure that grandma or mom or whoever will plug it in and it's also your responsibility when you walk out or roll out. However your get out of the door that morning that the devices is on the back of your chair because it's a lot more important to the students really than to the family, especially when their leaving home and going away.

CA I think another issue that affects whether of not it's taken into the community or not is portability. I think that if it's a really big system ,that's heavy , takes a lot to carry it in, and it's in the way it's probably not going to be used as much. One thing that I'm trying to think about as I help guide people in terms of what devices are best for the individuals is not only the device but the mounting system especially if it's someone in a wheelchair. I know a lot of funding agencies want to only pay for the least expensive mounting device, which is the one that just swings out this way. If the user is up at a table, then most of the time the people that are assisting take it off of the chair because it's swung out in the middle of the way for everything, so then it doesn't get put back on the chair. So I'm really try to support in my documentation for ordering systems the appropriate mounting system too, so that the system in just tucked down at the side of the wheelchair and is accessible so that when they pull back from the table it's there. Or finding systems where the device doesn't' have to come off of the wheelchair as much because I think that the more it's off the wheelchair the less chance of getting back on it for someone who ambulates with a wheelchair.

PC Or the other thing is making sure when it's positioned that it's positioned in a way that can if they have an electric chair or whatever kind of chair they're using they can get where they need to go with the device in place. We had-- somebody came in positioned the device and it was really great for communication but as soon as the child needed to go from one place to another. She couldn't see, so it had to come off, so somebody followed her anyway wherever she was going or it stayed wherever it was and not where it needed to be.

BP I think one of the biggest factors that I've noticed with family's- if the child is successful and can use their device and it's been integrated into their family life then it goes out into the community, but when the child is not using it. They constantly have to be prompted to use it. It's just another piece of equipment to lug around. Parents are loaded down anyway so if successful- it goes. It goes to the doctor's office. It goes to the grocery store. It's goes to preschool.

PC Another thought too, is that we have children who have electric chairs and manual chairs. The electric chair is at school and that's great. The nice expensive mount if fitted to the chair while when you go out and about in the community. You go out and about in your sometimes they go out and about in their manual chair so now you have a dilemma if you didn't order two of the part of the mount that goes up like this, the your in trouble. Then just being able to adjust back and forth sometimes is a problem.

BP I think if a family's had a positive experience using it in the community I think it can be sort of an ice breaker. The kid will initiate communication when using their device. Maybe they're in the grocery store or at preschool they can say hi and it draws other kids to them, adults. That's a positive experience. Parents are proud of their kids and it goes back out into the community.

SH: Okay, well let's start describing some of the greatest concerns that we've encountered in working with families during the AAC decision making process. When their kinda deciding about AAC devices what do you think their biggest concerns are? Barb do you want to start with that one?

BS How much is it going to cost? That's probably the very first question. They'll sit and listen to the entire thing. Their very first question is how much is it going to cost and until you can sit down and alleviate those fears. I don't think we can get into the ramifications of anything else. Then if the monetary issue is just so important to them also for being responsible for that just seeing the mechanical side of it almost more than the communication side of it. They heard from other people's experiences.

PC It think it depends on your SES level. I think because when Medicaid is paying and you don't have to worry about it. I guess all of my of my, well all but one or two people that I've interacted with were funded through some kind of Medicaid. The funding was there so funding wasn't an issue. I guess probably the only concern that I had that there was one parent who flat out didn't want their child to have this device because she didn't think that he needed it. The only way that we were able to get her support was to say that we're looking at this more as a computer that the child can use in doing school work. We knew ultimately the goal was to get it as an augmentative device that he could use all over and using it mainly for speech, but since she thought her child didn't have a speech problem her bigger concern was that he would look different or whatever.

LH Another concern that we see a lot of times is how am I going to get the support in the community, like in the more rural communities where they don't have access to professionals who do those or who specialize in it. That's real frustrating for me as a professional to know that this child is here and the family has invested, the child has invested. Now the funding is in place and there no support training locally. That's a real issue for us as well as the family.

BS You know one thing that we did a couple of years ago was we went back and analyzed all of the families that we pulled in from the very beginning in terms of funding. They would have to do something even if we were going through Medicaid. We made them fill out forms and sit down with us be really invested in obtaining the system and going through training and so forth. We found that those parents that we pulled in at every step of the way were they---- their children ended up being our best users as opposed to just like doing everything for them. This is what the child needs and if they didn't come to training we found that those were the ones that ended up not using the systems really as well.

SH: Okay, our next question is to discuss the roles of family members during the AAC decision making process? Who looks ready? Phyllis

PC I was hoping that you wouldn't call on me. As I said before, I think for most of the people that I work with they pretty much want to know, okay this is what it is and your doing it. They have a lot of trust in us and in many cases because I'm in a school setting and I've been in the same school for so many years. I've been working with that family. So it's kinda like anything we say and they don't tend to want to get real involved in it.

SH: Okay, Barb?

BS I think that they are invaluable in giving you some information in terms of how the child communicates in the child's communication needs in their everyday life: boy scouts, girl scouts, weekends activities, Sunday school that kind of thing in terms of vocabulary. What are the kinds of things you gonna have to think about? I usually agree. They are for the most part they are pretty trusting and will come to want we ask to and what we are thinking.

CA I going to make a comment again about users that live in I guess you would say institutional setting because a lot of individuals who are users don't always live in what we call a typical nuclear family. Some of the decision making that is made is made by myself as well as the direct care staff. I have one individual in particular who just idolizes policemen and wants to be a policeman in the worst way. I feel for this individual that one system is better for him because the output of the system is easier to understand. It's more intelligible. It has larger memory. It has larger capability and this person has a lot of cognitive ability, but the individuals at the facility want him to have one that hooks onto his belt and he pulls out. He kinda thinks of himself as a cop because he's got his holster. They want him to have that one because they think he'll use that one as opposed to the one that I personally feel is the one that really meets his needs. Sometimes when your making decisions -- what one person wants for one reason and what another person wants for another reason you often have to come to terms with that and make some compromises. I think often times we're also making compromises not only in terms of family roles but in terms of funding roles. Many times what we feel is best for the individual we know that there's not going to be anyone that will fund that and so we're also making some decisions on that with the family. Especially when you come back and you say that your family's first question is How much is it going to cost? I'm sure that had something to do with the decision making role in terms of

BS I really try to minimize that. I can honestly say that with all the families that I've counseled that I don't think I've had to compromise what we felt was best because of price.

Well, that's good

BS But it's because I work with individuals who are under 21 years of age. It makes all of the difference in the world.

SH: Okay, can you describe some things about AAC devices that tend not to be considered by family members?

VF I think one thing that is not considered my family members is probably the very first statement that was made, that Barb made. That is that AAC devices are limited. They'll only do what's programmed in them or what if we have a pretty sophisticated device and a pretty sophisticated user what they're able to do. We're going to get that natural give and take. Your not going to get that natural processing of formulation and response time that you get in just natural discourse. I think that's one of the biggest things that families don't take into consideration when their first hearing about the system.

SH: Anybody else have ideas about what family's aren't taking into consideration?

AR I think also there's going to be a certain amount of time that it's going to take to learn how to use this and to access it. Not like your going to take it home tonight and be able to have a conversation. It might take a lot longer especially when it's difficult to access it for the user. There may be a long time before you get more than four things. Four basic things to say. That might take a long time to store before you can move on.

SH: Okay

BS Wait a minute, don't jump ahead, something that comes up all the times is that there's a life span to a system. It can last until it falls apart and which can be years, but there also may be something else that come about in three years that's a whole lot better and then we need to pursue something like that. A lot of times they think this is the system and this will be it forever.

VF I think I do that myself. I want a perfect system right now, but working with the zero to three population I think the simpler device even if the child will have the potential of growing into something more complicated. I keep looking for greater development. What will come next? I think the easier it is to use, the better.

LH I find that some families look at communication devices as ways their children may be able to get across basic needs. It seems like a lot of them I first things that they want to put in there is I want to eat. I want something to eat. I want something to drink. With some people it seems like it not until we like really explain to them oh, this is something that they may be able to use at school during circle time or they may be able to use at a birthday party or until we really try and show them other ways that they can use this. Other than just meeting basic needs it seem like a lot of families don't even envision that initially, unfortunately.

VF Because often a child can communicate that in other ways. They already have systems to do that, so what a communication device can do is to refine and get complexity.

CA I think another thing they don't consider too. Again, I'm looking at family not only as the nuclear family unit but also in term of care staff. Is the amount of time that it's going to take just keep up with the system. Just to keep vocabulary appropriate, especially for individuals once they've moved on and they're able to access more and more vocabulary. And reviewing that vocabulary periodically you don't want to load the system down with vocabulary that no longer import for a number of reasons. It takes up the memory. It's more for the person to have to work through to get to the things that they want. So I think just in terms of the amount of time it takes to keep everything appropriate and working and I think that's often not considered.

BP I think sometimes they realize the hidden cost when the warranty expires. Is your insurance gonna cover the replacement ? Are they going to upgrade?

CA Because a lot of insurance companies if I'm correct will only pay for one for lifetime. Is that?

AR If that?

BP I don't know. I mean I don't know what insurance

CM I'm dealing with an insurance company. We will buy one for life and this is it. And that's part of that situation that you were talking about and that and that goes back I think to community education and also education of people who are buying the systems.

PC I think that one thing that people don't realize, unless we're unusual are the technical difficulties. When you think you have things working and then all of the sudden some kind problem and them for us we always try and solve it on our own thinking that it's a temporary kind of thing. We'll find out no it's major and it's the mother board and we have to send the whole thing back and I think it's. Maybe if I think of the devices of the students that I'm overseeing, some are worse than others. I think the more complicated you get once you start by putting head pointing systems on or once you want to use them as scanning devices. Those are the ones that we're having more trouble with, when I think of others and they're just using direct select and of course these are all Liberators because that's what's funded through Medicaid or the bureau. When you- the direct select we've had less problems so but that takes a lot of money because your sending it back and forth. Your paying even when it's under warranty and you paying for shipping and a lot of time and if you want a loaner and so

SH: What advise could you offer family member on how to better work with professionals when trying to identify AAC devices for children?

AR I would say once they've taken home the device and tried to work with it and things like it and come back with a written list of all of their questions and jot things down as they have problems. Come in with a list also to ask people who are instructing them to give them written materials to refer to because I think the instruction booklets are so difficult to understand. If they had a written more understandable thing that they could go back to because it's overwhelming to get all that information at one time and then think I know they told me this but I can not remember so if there's a lot of written materials that are more easy to understand that they can get.

BP I think making a list is a good idea and maybe come with information about in what situations does you communicate best. What are the sorts of things the child tries to communicate?

VF The written information would be helpful. As a professional I would not only encourage parents to call me with questions but to make use of the 800 number if there is one on the device. Go ahead and not be afraid to ask questions if they're not sure to what's going on, not to be afraid that it's going to break.

PC And also cooperate, still looking for the device or later on when we ask for the vocabulary give it to us. When we ask for pictures to put on the device. I think the more enthusiastic and cooperative the parent is I think the more we can get done.

BP I think to also ask parents to examine their own feeling about how much time can they honestly commit to maintaining this device? How do they feel about their child being on this device? I think that kind of information is important in making a collection.

LH It also gives the child credit for how he or she feels about using it too.

CA The question is what would you offer to family members as advice when trying to identify AAC devices. I think that one piece of advice is find someone that is familiar with AAC systems. It think that it's a growing field and I think that more and more people are out there that have a working knowledge of the systems that are on the market but I also see people who they only know one line of products so everything that they recommend is within that line of products when there may be another product that is better for that individual. So I think one of the basic places you need to start is finding professionals who really understand AAC.

PC Probably the other thing is to give the parents the confidence that really know their child and that they know the needs and make them feel good about that.

SH: Okay, do you think that the values and beliefs of the families that your working with are different from yours and if so how do these difference affect what happened when decisions were being made about AAC devices?

CA I think the example of me saying to these people, I feel this is the best device for this individual and they're saying oh but we think he'll use it more if he thinks he's a cop. I think that's a really good description of a difference in terms of attitudes when decisions are being made.

VF For me, I think it's your the professional. You know it all, well whatever you think is whatever we'll do. If you think this is what we the okay. Then maybe not being confident to say this is what I know of my child. You'll sometimes have people expecting you to know it all. Maybe you don't.

LH When Barb was talking about the family who didn't take their device out into the community, but used it at home. That as a professional would be very frustrating for me because I would know that especially knowing that's what the client used and it's hard because you want to give the family the respect to make their own decisions as a family unit. Also educate them as to why it's important for that person to have it across the community. It's sometimes difficult to know where that line is between saying yes, this is something to consider, but still having the respect of that family to do what they want to do.

BS And that's exactly what. As much as I as a professional would want to see that device being used all the time. I have a lot of respect for them as well. They have come a long way themselves. It's just one more major step. Even investing the money and they had to come up with the money because of finances. I mean, you know it was one of those things that was very expensive for them but they couldn't get funding through other devices, through other systems and so forth. They have grown a tremendous amount. I think it's probable just a matter of time and so it's respecting each other and working together.

SH: What changes are needed in AAC decision making processes to make it easier to work with families. Is there something that you can see that could be done? Belinda?

BP I think making the parents feel like they're part of the team and they're important in the decision making process and what they have to say is important and that you come to some conscious that everybody can live with. I think that has a lot of impact on how successful the user will be with using that device.

LH It's always kinda distressing to me and kinda a red flag when we have a child who comes in and the family will literally wheel their child over to me and say here that are when should I be back. It's always kinda concerns me, well we're testing their child and what we say is no we would like to review this preliminary questionnaire that you filled out and ask you some questions. Usually we draw the families in quite a bit throughout our evaluation. Those are the one that we know that we kinda have to draw in a little bit more because like I said they were thinking that something would be done with their child when it their opinions and their knowledge that we need to know.

CM So maybe we need to communicate to families in terms of this is how the evaluation process is going to happen. This is what your role will be and what our role will be.

BP I think that preliminary questionnaire that you send out does a lot in terms of making the families feel like what they have to say in important and their a team member.

AR Hopefully, they're starting to think about- what is it that frustrating to me? What is it that frustrating to my child? How can they communicate some things? What are the things they can communicate? So already they are starting to think of some ways that their child's communication can be enhanced.

CM Another thing to take into effect to is the users response to the system. Having them have a say in terms of system. I have some users who are a little bit older. They're not three, four and five year olds and I always try to bring in a wide variety of systems for them to try and frequently the users themselves have indicated to me in one way or another which system that they feel most comfortable using. I feel like in terms of those hurdles that we were talking about- if the user is involved in the decision making process from the get go we may get a little bit more quicker learning time or more ownership from the user.

VP I think ideally after the evaluation if a loaner was available to start trying, the time lag between an evaluation actually having the device.

PC Or making a decision to have an evaluation and having an evaluation. I was going to say I guess maybe for me and maybe for the families the decision making process could become more I don't want to use the word serious but, when it comes down to the funding agency is only going to fund one device or either one of two devices. One lower level, more simple and the other one more complicated. The whole process of decision making is really if you go through it, it's not fair to the family. The funding isn't there , so why are we making such a big deal about this decision. It's more a matter of do you need the device or don't you and if you do? You can have this one and if your cognitively higher and need a more complicated device than that. So maybe we need to go a step back and one of our problems in the funding source and we need more options that are real options, not just oh these look nice, but you can only have that.

CM Getting through to funding agencies and trying to educate them is really hard and especially with the cut back of the health care dollar now. They're wanting, all at once the technology is just exploding for these systems. They're much more user friendly. There's a lot more options on the market so as the options here are going up the funding is going down. That's a real frustration.

SH: Okay, I would like for you to think now about when you've worked really well with a family and a time when things didn't work very well and see if you can describe what was different. What you think was different for the families where things went well. It worked out. You got the device and things were going well as opposed to when it did not. Laura can you think of a

LH I can think of a families that it's almost both that situations in the same question. If that makes sense. We had a family- the child's mother who ended up taking us to the home school program. Initially, a lot of what was happening was just the mom's readiness in terms of knowing that it was really truly going to be a long time for her child if he ever was going to be able to communicate verbally. We had mentioned a device to her and it was six months to maybe year after we had initially mentioned it. We would just kinda keep bringing it up every couple of months. I would really try and giver her concrete examples to make it clear in her mind. So. initially it was a bit frustrating. I was trying to put a lot of it back on myself thinking why isn't this woman understanding. Am I not communicating to her what it is that this can do for her family and for her child? Then when I realized that she just wasn't ready yet and I just needed to take a couple steps back and just make sure that I had done my job in educating her to the things that were available and the options and what it could do. I found that the more I stepped back and let her mull it over, she was finally ready as she came to that conclusion. Once she really saw and got a loaner device she really took off with it from then on did quite well, but initially it was just her readiness in terms of accepting her child's disability and the things that he would need and it wasn't that she was giving up hope. She still hoped and we all still hoped that he would be able to be more verbal, but, she was just kinda setting her hope in another direction.

CM I agree with you. I think that it's in a nut shell.

SH Anyone else share about someone they have worked with?

VP It really becomes so vivid. I mentioned the lower socieo-economic problem where the mom didn't make it to the workshop. Her car broke down then she didn't make it to the next one. We got the device, and then the child, I was no longer able to work with the child. The child was really relaxed in our setting and was making progress. When she went to school, I think her physical ability to use the device changed. She became more physically involved- could not actually access the device. As far as I know, it's sitting on a shelf somewhere. I'm really sad about that. I no longer have contact with the family. I think possibility that given a different SES level maybe the mother would have asserted the user getting something different. I don't know the situation right now, where that is. The best one is a child that's not quite ready for a device. Maybe he is, but he was banging at things and very playful. He can communicate by some vocalizations and his eye contact. A lot of a great variety of things and we just finally made progress in getting him to start to use some non-activated voice device. He pulls a word or a wish off of something with velcro and then hands it to you. I can see in a very short time he's going to be able to use a device. He's about five now and he's getting close. It's very thrilling to see how close he is now to be ready to access a device that will open a lot of doors for him.

BP I can think of a very positive experience where both the mother and I, we weren't quite sure how this child would do on a device. He was closed head injury, visually impaired, and very young, but we knew that he was trying to communicate and was having a lot of difficulty with that. We started him out on the alpha talker and he just took off. We were amazed at the things he did with it. It was so satisfying to see how happy the parents were. It was just one of those times when you-well, there a lot of times a guess when your not sure how well a child is going to do. This was one of those times it worked out really well. On the flip side of that, I've also worked with families who have been very frustrated with the lag time . They get so geared up and their ready for it and then waiting on funding or whatever that can take time. It's hard for the families to have to wait.

SH Anybody else have a success story?

CM We could be here all night

SH Is there anything else about the subject that I haven't asked you about that you want to talk about today? Talking about families and AAC devices or

BS Well, you focused on families, and devices in the community, and so forth but and we all talked about it but, how important it is- the attitude of the user. If they're not interested or don't have the skills or aren't motivated. You can dance all the jigs in the world and it's not going to be successful. So, I think that not only motivating the family, but motivating the user is critical.

VP I think you mentioned, makes me think about another thing. I think one of the questionnaire brought that up a little bit. That would be a support group. Perhaps communication groups using the devices for either the families and or the children would be if it's not, it would be a really nice next step in communication.

PC One of the problems that I see and again it the training for the Prentke Romich devices is that they have that training that they offer. I've gotten to where I could barely send teachers, let alone parents who not highly educated. When I think about it that's really not what the parents need right then, especially. They don't need a very technical description of what this is. I think they need to know the capabilities of the device is, but also how to integrate into their house and their family. I think that's missing. We should be able to get them to come to the schools, but I think that would be real helpful if we want to integrate the devices into the home. We need to show how they can be or even with other teachers or whatever. We need to know the technical way of how the machine works. Another thing to know is how these devices can be integrated into everyday life and
sometimes is missing.

BP I think that is so overwhelming and so intimidating that it scares a lot of parents off. I think the support group is a great idea. Both for emotional support but also for educational support for families. I think they would benefit a lot from just on going workshops where you can talk about a small little piece of the pie and not hit them over the head with everything, then send them out there on their own. I think that's what a lot of parents feel like.

LH So they can learn from each other different ways to integrate them into their family.

CM Sheila, you have a lot of extra time you can just start one here.

SH I was just wondering if anyone had any ideas on how that would be started? Could it be through the educational system, the hospitals, or home health or is it just going to take parents themselves forming a group?

BS I think you have to do it locations wise. We saw what happened with MAX and that's professional. It's like you can't do it across the state, or from region to region, or anything like that. We do it somewhat in our district. We have found that we still have to get geographical. We have to divide them geographically as opposed to by the system. We used to think okay Dynavox, Liberators, and Alpha Talkers and that's not what's important. They can't drive very far and they can' meet very often because it takes so long to program these devices and plug them in and everything else. We've heard all the excuses.

CM It can't be on brownie night. It can't be on basketball night. It can't be on choir night. I think that's one thing that we didn't bring up is that as our world is moving faster and faster and more and more demands on the family. I think it kinda was brought up the fact that this is another demand, but I just really get the sense that our world is moving to so fast and to ask people to do more and more is getting harder and harder.

BS You can ask them, it's the response.

CM And again it's back to that motivation and the attitudes and what's important.

AR I would agree with that. I have a whole new respect for what families go through, going into their home and seeing the incredible about of care and time these kidos I basically see pediatrics, but what they need day in and day out. It really made we change my whole home experience program and all of that. I'm going to have the two main things that need to be done, instead of ten pages because I thought is was realistic. I think the same thing with communication you know if you can find the system that gives you the most options and the least care and the most convenient. You know that's really important, because you know we don't know what it is like. They know, they're going through it. So a support group to where they can say we got this one. It wasn't this bad and this is how we did it. I think that would be great.

CM Getting families hooked into support groups before they even purchase a system or before they're even bought so that they can- some of those things we were talking about in terms of what are their expectations and are their expectations realistic could maybe help them to work on some of that before systems even arrives.

AR And maybe you guys could include that in your questionnaire. Would you interested in joining a support group? Start that there and then send that information to

BP First Steps now funds assistive technology and assistive technology training. If your providing services in home, that's great for families because you can go into their home and work with the child and give the parents some extra training too on the device.

If they want us there

CM Are there any on line support groups. Is there anything going on line in terms

That's a good idea

CM Well again that takes more time to figure out how to get on line, to get on line and do all of this but

PC After you get the funding for the computer and service

SH Thank everyone for coming today

Focus Group with Families without AAC Devices

March 28, 1996

Sheila Hostetler, M.A., C.C.C., Moderator
Children's Hospital, St. Louis

Summary Background Information

Type of Group: Families without devices focus group; conducted by Sheila Hostetler

Date Conducted: 3/28/96

Where Conducted: Children's Hospital of St. Louis, Room 5E8, a conference room adjacent to Therapy Services

Number of Persons Present and Roles: Riva Starks, mother of an 18-year-old daughter who was hit by a van at age 15, uses a wheelchair and Alpha Talker; **Shaun Patton**, father of 6-year-old daughter born with Joubert's Syndrome who uses a Delta Talker; **Debra Beal**, mother of a son who is four and a half who is undiagnosed but may have apraxia who is considering the Dynavox; **Shelly** and **Tom Neupert**, parents of a 5-year-old with cerebral palsy and right hemiplegia who will be receiving a Delta Talker; **Michelle Jackson**, mother of a young child with tracheomalacia, a narrowing of the airway who is learning signs, and who is scheduled for an upcoming AAC evaluation.

The moderator was involved in the assessment of all participants' children. Some participants had difficulty understanding and completing the forms, and found the questionnaire to be difficult. One mother was confused regarding her membership in the ethnic group options presented.

Logistical Issues: This group was difficult to schedule-everyone wanted a different time, i.e., am, pm, evening. Group was scheduled around time convenient to Riva who had baby-sitting/nursing issues. There was an intense rainstorm the evening of the focus group. Three individuals who planned to attend did not show up as scheduled. Individuals received questionnaires ahead of time and brought them to the focus group meeting site with the exception of the videotape release form. Homemade cookies and soda were served.

Modifications Required in Protocol: The protocol was closely followed. Some individuals had problems in understanding and completing forms.

Synthesis Statements

1. Family Expectations

- To see changes in child's behavior (reduce frustrations)
- Increase child's self-sufficiency and happiness
- Increase communicate abilities
- For child to be consistent in device usage and then learn to use a computer
- To provide a "window" out of a trapped body
- To enable child to express needs and feelings
- Device will facilitate peer acceptance
- Will allow child to communicate "pain" during therapy

2. Change in Home Environment
   - Device will increase time demands on family
   - Device may free u family time after initial training period
   - Child with history of medical equipment usage may readily accept new device
   - Device weight requires family members to transport it
   - Device will increase responding time for child and family
   - Training commitment to use device may be initially be overwhelming to family

3. Stress and Families
   - Device may result in no change in stress levels
   - Device may result in decrease in stress level in home
   - Device may result in increase in stress level outside home

4. Community Issues
   - Wheelchair mounts inhibit access in community settings
   - People in community need education about aac strategies
   - Expectations of peers and child's inability to exhibit behaviors appropriate for child's age may present problems
   - Parent may take device everywhere
   - Device may draw attention to child in community settings
   - Other children will express curiosity regarding device
   - Transportation may be an issue

5. Working with Professionals
   - Child may refuse to participate in evaluation by using defense mechanism as response to new team members
   - Mom must help facilitate rapport between child and professionals
   - Professionals need more information about AAC to inform families
   - Need for more 1-on-1 with therapist with experience with AAC
   - Teacher may be apprehensive regarding AAC responsibilities
   - Family expects professionals to be on child's team or get off team
   - Speech/language pathologists may not be trained to deal with child's AAC needs

- Professionals must value information provided by families during evaluation process
- Adaptation in testing procedures may be necessary
- Professionals should establish rapport prior to testing
- Insurance companies base decision on evaluation information
- Therapist should not assume responsibility of being liaison with hmos
- Families expect information from professionals about AAC
- Families need information regarding timelines in AAC process
- Professionals should facilitate children's acquisition of devices to enhance child's quality of life
- Teams may need to involve specialists
- Child needs continuous access to AAC from time of rental to actual delivery to family
- Professionals should not give child a means to communicate and then take away
- Children may lose important motor skills after initial rental
- Professionals shouldn't position children and then remove clinical posturing necessary for AAC access
- Professionals should not limit child's ability to fully participate in school activities
- Device purchased for school may be used with may children, but fails to fully meet an individual child's needs
- Professionals may need to work with siblings in family to appropriately use AAC device
- Professionals should clearly communicate information regarding short term AAC strategies during repair periods and while waiting for receipt of devices

6. Values and Beliefs of Professionals
    - Not enough gate keepers of AAC information; families don't get what they need
    - Professionals should recognize immense responsibilities of families
    - Professionals don't have exhaustive knowledge base which can be problematic for families

7. Changing Family Roles
    - Child will be more expressive with AAC
    - Siblings must assume new communication responsibilities
    - Child must learn "give and take" with added communication competence once child is "fixed"
    - Child may become more demanding of family members
    - Family will be able to use causal conversation with child on receipt of device
    - Family may have to be assertive and change therapists if family goals are not being net
    - Families should have high goals to ensure best quality of life for child; professionals should not allege that families are in denial when high goals are expressed

8. Family Relationships with Community

- Community may perceive mother to be "super mom" for being able to implement AAC
- Family must train other in the community
- Family wished support had been available in community
- Family desires that child be able to communicate fears or need for help when threatened
- Families have concerns regarding who will be responsible for devices that go to school
- Families may have to take out insurance rider to cover devices used in community settings
- Family may need to work with vendor to secure underwriting
- Hospital personnel need basic AAC knowledge base
- AAC device usage is worthless in absence of supports
- If parents are adequately trained and used as resources, substantial savings in medical costs can be realized
- Parents should be involved in research and development activities by manufacturers

Transcript

SH Let's go ahead and have everybody introduce themselves. Riva do you want to start and talk a little bit about Jennifer?

RS I'm Riva Starts. My daughter, she just turned 18. She was hit by a van when she was 15 years old. She was an A student, athlete, and she was coming home from one of her practice sessions and the guy was speeding. She was comatose a year. She sustained shearing of the brain stem and hematoma. She is in a wheelchair. She is kinda defying her prognosis right now. The neurologists are in all of her because they did not expect her to do anything. Not only is she communicating, but she makes jokes so we haven figured out how that came back so quickly. The Alpha Talker was something she just qualified for because we discovered she was trying to communicate with us through eye blinks. That was something really she didn't have enough therapy to learn through the HMO dropping her. She kinda acquired it real fast just from us and then the therapy came in and backed us up. Then it was this kid needs a communication device. That's her little story.

SP My name is Shawn Patton. My daughter Kayla, she's 6 years old. She was born with the syndrome called Jourbette Syndrome. It's a genetic malformation of the cerebellum is the one of the main symptoms of it. So she's wobbly. She doesn't have real good coordination. Her fine motor skills are kinda rough. She's non-vocal. Up until just recently, we didn't know how intelligent she was. She's learned some sign language but because of her inability with fine motor skills she has a real tough time. This has become a behavior problem because she gets frustrated so we came in for a augmentative communication evaluation, When I heard her do the Delta Talker, it's was like her own little voice. I kinda got misty eyed like because I had never heard her talk before, but I'm really hoping that she will be able to express herself and we find a lot of hidden intelligence with it.

(Michelle Arrives)

DB My name is Debra Beal and I have a son who is four and a half. He is undiagnosed pretty much to this point. We're not sure why he doesn't talk. They think maybe he has apraxia, but no one really knows for sure. He understands almost everything you say, he just doesn't talk. He has only like two words. He's just getting really frustrated not being able to communicate or say what he wants or needs. Potty training has been a real problem because he can't tell you what he wants so we're looking at the Dynavox. We're just hoping that it's going to make him actually start talking just some of the frustration that he has of just not being able to talk. Being able to express himself, he'll just kinda start talking hopefully, eventually since no one knows what's wrong with him.

SN I'm Shelly Neburn and this is my husband Tom. We have a little boy. He just turned five last week. He goes to Parkville Elementary. He's been diagnosed with Cerebral Palsy. He's a right hemi., but he has maybe a 50 word vocabulary.

TN yeah

SN He's got about a 50 word vocabulary, but some of it's only understood by us. So he's in desperate need of a Delta Talker. He's starting to talk in sentences now, which nobody can understand. So he's a talker, he's just - you just can't understand him.

TN He does some signing.

SN He does a lot of signing really.

TN yes

SN He has a real expressive face, so he's not really frustrated but sometimes it's not to festive because if he was frustrated he would try to try a little bit harder, but he's just real content calm kid.

SH Michelle, do you want to say who you are and tell a little bit about your child?

M Not right now

SH Not right now, you want a little break. That's okay. Well, I'm going to ask first or just kinda what your goals or expectations are for the AAC device that your child will receive. I know in your case Riva, your child has gotten hers, but just think about what your goals are, your expectations when you get the device. Shawn you want to start and tell us what your expectations are?

SP I would really like to see a major modification in her behavior. I know that children with a disability that she has in particular have real behavior problems, but I've seen her behavior. It has greatly improved since she learned some sign language, but it's not enough. She isn't able to do a lot of signs that I don't understand because she's not very articulate. So I would really like to see her, we have a hard time taking her in public because she gets so frustrated- temper tantrums and stuff like that. So I would really like to see her behavior improve. I would just like for her to be more self sufficient and happier with herself.

SH Okay, Shelly what are your expectations when you get the device?

SN To be able to communicate. He tries so hard to be able to communicate everything to us. You know not to get that look, did you get it mom? You know? Or can you tell me again, it would be so much easier to pick up that device and at least sometimes you know you don't understand what he says, he tries to take a word that similar and ease you in or take you hand and show you. So I think that if he looked at pictures on a device that would, he would really be happy. You know and I would be happy. He does like if you don't understand him and you ask him a couple of times you know mommy didn't get it. He'll just give up and go play you know.

SP He does what he can.

SN Yeah, he does what he can.

SH Riva, what were your expectations?

RS Oh gosh, the moon. Jennifer is shocking us with her rate of recovery because she's changed since you saw her last. We discovered just recently with the Alpha Talker that Jennifer has to have a certain kind of stimuli and once we put it in place she started to us it. So I would say that I would like to see Jennifer at the age she is be pretty consistent with the Alpha Talker and later on I would like to move her on to a PC. I have the equipment and it's adaptable to it because her, we know her intelligence level is there and we tested her. She's just trapped inside a body that doesn't work. So I would like to give her a window out. I think the Alpha Talker will do that for her. Since she's gotten it recently, I noticed personality changes and we've recorded them. I think that's really significant that a device could change a person's personality that fast. Those are my goals for her.

SH Debra

DB The sky's the limit, definitely. I have lots and lots of goals actually. In the beginning just being able to say what hurts, or what he wants or ... It's the most terrible feeling for your kid to be crying or upset and not know why. It could be absolutely anything and you have no idea. To have them pull you around the house trying to figure out what he wants and your not getting it right is unbelievable frustrating for me. I can't imagine what it must be for him. Just everyday needs and wants that he'll be able to say what he wants in the beginning. It's been hard to tell like

- we know he understands what you say, but as far as like the alphabet, and colors, and stuff. Without him being able to respond it's been really hard to tell exactly what he is all taking in and with getting ready for kindergarten I'm just hoping that when he gets this it's just totally takes off. I think that it will. He's not um, he has a hard time with his peers because he his own age because you know they're talking circles around him his little head must just be swimming. I'm hoping that it helps him with peers too. He's still pretty little, but I think his peers would take to it and accept him as little as he is. It's not like being a teenager um I don't think. He had the Dynavox for a rental period for a couple of weeks and took it around with him. His little cousins and everything just thought it was the greatest thing. They all fought over it, so hopefully it will just break the connection with his peers too. It will help him talk to other kids.

SH Michelle do you have any thoughts on what Devon might you know gain from an augmentative device?

M I don't know yet, because before he can speak, they have to do surgery on him. He has tracheomalacia, a narrowing of the airway. He's learning signs. He does pretty good with signs. He takes you into the room, pull you across the room, but basically when he wants something I can tell. I don't know why, but I can tell what he wants. He'll point to something and I'll be like - what do you want? He'll sign something for his bottle or eat or toy.

SH Do you think he'll like have the voice output device? Do you think that is something that he'll enjoy too?

M Yes, if you ask him to talk (makes the face and a sucking noise). His voice gets louder and louder. My girlfriend is like, she said god Devon make a lot of noise for not being able to talk. I said shhh, I told him to be quiet the louder he gets. I'm like oh boy, wait until you start talking.

SH He might really enjoy having a device, okay. All right, the next thing I'm talk about is we're gonna kinda explore ways that the augmentative device might affect or has affected your family. I'm going ask first a little bit about the organization of your home environment. Kinda how the way your home is run- are you going to see as a another thing your going to have to add to your family life or do your think it will make it easier or harder? Kinda what your thoughts are like on your home environment. Tom, I'll go ahead and start with you.

TN Well as far as regular operation in the home and everything that goes on I don't think that it will make a real big impact because right now at least in the home he ambulatory and everything. S so we pretty much know what he wants and he's able to let us know what he wants. A lot of times if we don't understand what he wants we'll ask his little sister what he says. She'll say oh he said that he wants the green thing or cup or something like that. We can understand right away, and she understands what he says, but I think it might have an impact on just the our time and our availability in the home spending more time trying to learn how to use it and make it more accessible and easy for him to use outside of the home and with other members of the family. So trying to make him feel at ease with it at home, so that when he takes it out or has other people come in with it or takes it to school he's able to use it more readily.

SH Okay, Shawn what do you think about your goals?

SP I think it's actually going to free up a lot of time for us. I don't think it's going to be, past the initial training period of how to use the device and maintain it. I think it's really going to make our lives a lot easier. Right now we spend twenty percent of our time just following Kayla around trying to figure out what she wants. Trying to appease after she's already been frustrated and thrown a temper tantrum and normally it would have been just something if we knew what she wanted. We would- it would be a whole lot easier. So I think it's going to free up some time for us.

SH Riva, do you have any thoughts about how it affected your home yet? Has it been a pain?

RS I think it is going to be a lifesaver with Jenny because she's in a transition stage she has a huge team of therapy. She has two step of teams, one here and one at home. The they reason that occurred was because of the change in her neurological status. She's getting ready to go into standing devices and all types of equipment. We need her to learn how to communicate so if something hurts her or if she's having trouble accessing to something we need a signal. Even though I can understand everything she's doing and saying and I can read her. I with her like that in comma, I could understand her, if she was in trouble I knew just looking at her, but people who have spent 18 years with may daughter -a therapist walking in cold on the scene has to rely on me. Now, if Jennifer has a way to communicate and an out to say that hurts or I don't want to do that, even or I don't feel like doing that today. Then that will really put her therapy, it will just move it forward so much faster cause we discussed that among the team. We all feel that Jennifer needs and is struggling to come out of this trap she's in so she can let us know what's going on because she let's us know when she's wet. She let's us know when she's hungry. She has a sign for it, but she doesn't have the motor skills or the communication skills to do pain properly for other people. We need that right now. It's a medical necessity. The school needs it, because it been in situations when she's been in trouble where we've had to rush her to the hospital and then when we get there, cause they couldn't get me and they didn't know what it was and it could have been something simple. So we really need the Alpha Talker for medical reasons and safety issues. It will make her feel a lot safer.

SH Michelle do you anticipate having any problems having to incorporate it into you home. Do you think it will be bother or an asset or just not sure yet?

M Well Devon so used to having machines around when he was younger.

SH Having the trach?

M Yeah, having the trach. His toe socks he used to have, he would turn it on, turn it off. The other day I put it on his toe just to see what his iso level was. He still was taking it off and pushing the button. He'll probably this think it equipment.

SH Just another piece of equipment.

M Because he knows how to bag himself and everything.

SH I know Debra, you've had one for a little bit. How did that work in your home environment?

DB It was good. I like the fact that a lot of times it's just me that try and figure out that hopefully other people, other family members won't feel so uncomfortable taking care of him for me when I leave him. It's real you know nerve racking for me to, whether I'm wanting to know whether they're going to be able to figure out what he's trying to say. Just for the environment- the biggest concern I have right now is the weight of the device. The old Dynavox that we had for the rental. He couldn't have begin to even push the thing across the table, more or less carry it from room to room. We didn't even send it back and forth to school because it was so heavy. I was afraid. I just didn't do it. The new model is not supposed to be as heavy, but in the beginning that is still going to be a concern for me. Him, the heaviness of it being more of dragging us down or leaving it behind because it's to heavy to carry or whatever. That's, at this point that's my biggest concern about it, but that would be it.

SH Is anyone concerned that it might affect your time? It might be more demanding on your time? Riva your laughing, is it adding to your time?

SP You have one right now?

RS Yes, I'm just laughing because Jennifer has so much equipment in the house that the Alpha Talker is just like- I mean

SH You haven't felt like you've had to spend extra hours

RS No, cause the house has turned into a rehab place. My living room

SN I think it will speed up your time.

SP Oh yeah

SN You won't waste your time trying to guess what everybody's saying or what he wants or find another kid to tell you what he wants or you know can just

DB In my case the Dynavox is, the program of it is unbelievable. The rep says that technically we're only supposed to get four hours of training and he stills says that's not enough. Well, when he said that I was like --- you know I'm really like I think I'm not prepared for this at all in the beginning. Programming everything in the Dynavox is going to be totally overwhelming and will take lots and lots of time, but once it gets set up I think it's gonna be a breeze and I won't be able to figure out how I lived without it. In the beginning I think it's going to be totally overwhelming.

SH Any body else have any thoughts? Okay, gonna ask you a little bit about levels of stress in your families. Do you think having this device is gonna to affect the level of stress which you currently experience. Like is it gonna make it less or make it more stressful in your home to have a communication device. Shelly?

SN I think just in our immediate family it will be wonderful. I think when we take it to Grandma's I think our parents are going to be a nervous wreck. Where's his box? Don't drop it. I think they're gonna be- I think it's going to be overwhelming outside your family like grandparents, aunts, and uncle but in our home for me at home I think it will be a lifesaver.

SH Michelle, what do you think about it? Is that going to stress you out having another thing because he's already got so many things?

M No not really because he's so used to having like she said stuff in the living room when he was younger, when he first came home from the hospital, but now everything is cleared up but the oxygen tank. So I don't think it will affect Devon, cause all of his other stuff is gone. He don't use anything now.

SH They gotten rid of some of you'll get a new one and life goes on.

M The only thing he's got now is oxygen.

SH Okay

M It shouldn't be a problem. My mother and them probably will. Like she said outside the family when you go to a relatives house they probably would.

SH Shawn, what do you think about adding stress to your life or decreasing stress?

SP I think it would be hard to add any more stress?

Group laughs (as if they all seem to agree)

SP It's hard to say since we don't have a device. We haven't even trained with one or had a rental or anything like that. I think it's really going to be- it's going to decrease our stress levels a lot, but it could come down to her sitting over in a corner with the volume cranked all the way up saying words over and over and not going to bed. It's hard to say, but I really believe the way I see it, it's really going to decrease our stress. We'll know what she needs instead of her banging her head.

SH Debra, what do you think after your rental trial?

DB Actually, um stress wise, I don't think it's going to be much different probably just about the same. I'm by myself with just him so there's not other kids demanding my time or anything. So actually I don't-- I think it will be about the same.

SH Okay, Riva how's the stress over there in your life?

RS It didn't add any stress. It really it's a fun tool for us. The speech therapist has put these strange commands on it and Jennifer gets a kick our of it. She wants to hit this one that says "get out of my room" all day long. So it's fun. It's gives us something to play with, and something to mess with us with. So it actually gave her a little weapon.

SP She might need a little weapon.

RS She might

SH I'm just going to ask you now a little bit about taking your child into the community and if you think it might be helpful as far as going places like restaurants or any kind of social or recreational activities if you think that's going to add.... Riva I'll go ahead and start with you, now I don't know how often Jennifer really gets out. She goes to school, but..

RS We are going to have some problems with that. The problem that we're having in the house now is the mount on the wheelchair with the Alpha Talker and the travel of it. I think in my evaluation I've been working with another rehab medical who's supplying some of the mount. There should be some more accessibility to those mounts because some of them create pure hazards through doorways and stuff you know. I don't know how you pack up a child with some of the mounts they provide for wheelchairs. You know, we've had trouble.

SH So you feel like if you get the mount problem solved it will-- you can take Jennifer out to use it.

RS I think those need to be re-evaluated because some of them- how are you going to get a child a big child or a small child up to a table with that thing sitting up there because you can only anchor it a certain way. Not everyone's wheelchair has limited devices on it, like my daughters wheelchair. You've seen it. It's full of stuff. We've had trouble working with those and we still are. You know but we're trying to work around it as much as possible, but taking her out in public is going to be ruff. We're going to have to do some things to try to make her fit in places.

SH Okay, Debra what do you think? Is it going to be something that he can.... you mentioned it would be hard to carry maybe but...

DB Yeah, carrying it around still as little as he is, but overall I'm really into educating people who are ignorant to just kids not being able to talk. It's just, he understands so much, it's really hard for people to understand how when you talk to him he understands he just can't speak back, but actually I'm looking for a lot of people staring and stuff but I think it's natural and understandable. Right now I don't think he would care much about it, but once he gets a little bit older I think it might bother him, but I'm really into trying to educate people, other people about devices and things that they can do for kids. Either people aren't going to accept him or a lot of people- just there just so intrigued by it so far. Family members- I've been telling them about it and they just can't wait. They think it 's really neat, but it will be different. It will be an experience I'm sure.

SH Tom, what do you think?

TN Well, I think as far as us going out to get something to eat or something like that probably-- we won't probably we won't use it a whole lot in that type of a situation, but as far as other aspects and socially if he takes it out. One thing that I think we have a little bit of concern about is he's-- our teachers and our therapist have always said that he's real peer pressure oriented and if he sees-- he'll do something cause they other kids are doing it. That's his big driver more than the teacher or the therapist working on it and that's lead to a lot of his successes and if that and it hasn't happened so far where it's been a big negative or anything. Like he has trouble with his drooling and things like that, other kids may ask a question once or twice, you just tell them well he just has that problem a little bit and his sister helps him out and everything, It's not really a big problem, but that's one thing that might, he might get his feeling hurt or something like that if another little kid does something. So far it really hasn't been a problem. Just not being able to talk out and that you just kinda explain it. Most little kids his age go, oh okay. It's no big deal and go ahead and keep playing with him, but the older kids and that I guess it's a little bit a concern.

SN I think I would take it everywhere during the day because I would have the time to program it and tell Tommy we're going to McDonald's, gonna have a hamburger you know what I mean but I'd have the time like in the evening I don't know if it would take me.. I don't know what I'd do with it.

SH Michelle, I don't know if Devon goes out much now, but can you...

M Yeah, he goes out and like they said people stare at him. They'll say your baby have a cold? I'll say no he has a trach and then they be looking for the trach and sometimes you can't see it because it's covered. Then I'll say Devon show them your trach and he'll go . He'll open his and show them his trach. A lot of kids will come over and play with him. The adults basically stare but and then we sit in a restaurant and I have his machine. I'll turn it on and I'll suction him.

They'll be looking and I be like be needs to be suctioned. He's got a trach. You know you get tired of people looking at you, staring at you. You're wondering why they're staring at me, it's just a baby. That's it. They still stare at you anyway, but I sit there, I used to, my friends used to tell me or my sister- you should go in the bathroom. I'm like why, I'm not afraid of anybody seeing me suction. I suction wherever I'm at now.

SH So you kinda perhaps see Devon as maybe taking his communication device with him if he got so he used it.

M yeah, probably yeah

SH All right, Shawn?

SP Well, I think we're going to take it with us everywhere. um I think it will really help her behavior because she will be able to express herself. There won't be temper tantrums and stuff like that. As far as, I really haven't had a chance to use the device, but I don't think they'll be any.. I don't think she'll be stigmatized by it. I think it will be more of an ice breaker if anything especially with children her cause they'll want to know. I mean.. the children that she's in school with right now aren't special needs children. It's kinda an isolated classroom that she's in, but those children have really warmed up to her. When she can't talk they just now that she's got to communicate in a different way and I think this will ... I think she'll take it everywhere she goes. The only problem is that with her handicap she's not real stable on her feet, so I don't know how she's going to carry it. We may be looking at a support dog to carry it around for her.

SH Okay, I'm going to ask you questions about professional now. I want to know what have been your greatest concerns in working with professionals in getting your child's AAC devices. So like speech pathologist, occupational therapist, maybe physical therapy so think about if you've had any concern in working with them, what those might have been. Michelle have you had any concerns in working with Devon's therapist or professional people? Have you felt like they were trying to push you in a direction that you did not want to go or have you been pretty satisfied or?

M I've been pretty satisfied. He hasn't had, Devon has not I guess all he needs is a speech therapist because his doctors, his surgeon, his pediatrician they all.. I haven't had any problems. I haven't had any problems.

SH Riva, go ahead. Tell us about your concern in working with people trying to get the device.

RS I just have one. The one that Jennifer exhibited for you when you were evaluating her. Jennifer ah she, when she meets new therapist and new professionals people she plays possum with them. She does it deliberately. We used to think that she couldn't help it, but we're evaluated her and she does it on purpose. It's her defense mechanism. She sizes you up that way. She just kinda looks at you and she won't talk. She'll hold her head down, so we need to keep consistency while we're trying to train her on this talker because she can take weeks doing that until she decides she's going to deal with you.

M When you get new therapist?

RS Uh huh, and we feel like in a transition like this in adaptive tune her talker. If we start switching therapist to much we'll lose time and progress just because of that little personality trait we can not get her to drop so. If I'm in the room I'll tell her and we joke around like we did in her evaluation she'll eventually come around, but I'm not always going to be there for those things.

SH Do you remember what kinda inspired her during her evaluation?

RS Oh do I. I had to do a rap song and I hate rap. I had to do one and she started to us the switch. All the time while we were working she was just kinda looking going- I don't know what's going on but I'm not talking to any of you. I'm just going to look at you, but when mommy made a fool of herself she came right along.

SP You had to make a fool out of yourself?

RS Yeah, and laughs

SH You know I think what gets her is what's motivating to her, you know. The rap song is motivating to her and the things that we thought of probably weren't.

RS They did. They did.

SH Okay, Shawn what's been your experience in working with professionals. I know that your daughter has a speech language pathologist as a teacher and she's probably guided her.

SP Since she was about eight months old we've seen everybody form a physical therapist, to occupational to speech, the works. I haven't had a bad experience yet. Some of the professionals that I would be more concerned with are the actual doctors. A lot of times cause you don't want to hear the prognosis they give maybe, but as far as the therapist and I'm not trying to butter you guys up, I don't know but there has got to be another motivation behind why you guys do your job. They way you guys treated my daughter. It can't be for the money.

RS That's right

SP So, I don't know, nothing bad to say about the professionals we've dealt with.

SH Debra what do you think about the role of professionals in trying to get a communication device for your son.

DB Actually it varies so much. I would say in the beginning my biggest thing was why in the world didn't someone tell me this sooner. No one told. No one ever once said to me, have you ever thought of an augmentative device. It was something that a friend of mine got for her daughter and her daughter was like way behind my son and I thought well if she got one my son is understands and comprehends way more. It was something that I initiated the whole way through myself not one doctor ever mentioned it to me or anything. That would I think this could have been done a whole lot sooner so I mean. That's one negative thing. My concern with his immediate therapist that he works with on a daily bases is um their time um of course I don't think my son gets near the time he needs one on one. That would be the biggest thing is just the time. I don't think he gets near enough time from his therapist. His therapist right now is extremely open to the idea of it, but she's um never, hardly ever worked with one. She's a recent graduate. is excited. She's trilled to death that one of her kids is going to one and she's going to get to use one and have the experience, but she basically has no experience at all which make me um She's very enthusiastic, which makes me thrilled on one hand and but no experience scares me also. His teachers are totally overwhelmed by how much the Dynavox will do. The programming of it. They're excited, but they're extremely overwhelmed and I'm not sure how they're going to take to it. Just um a lot of different concern depending about which professional you talk about um neurologist was the same way, never said anything about it. um The therapist themselves I think are much better. The doctors need to uh I don't know if they're afraid or what but that's their job and that's what I pay big money to go see them for. I go there for answers and they're scared to tell me what they think I guess. I don't know.

SP I feel the same way. It seems like there is a gap between where the doctors leave off and the therapist because the doctors..... They're doing a great job too, but they never.... from the professionals the doctors there was never any mention of getting a device like this. It was through the therapist.

M Now see, it was totally opposite for me

SN Yeah me too

M Dr. Lo's told you all to call me. They're always to me they're always thinking about Devon, Devon, Devon. What's best for Devon? So I never had that. Anything that comes up

SN Our neurologist wrote a prescription for one, because a lot of times if they write a script then insurance companies have to provide it. He, I think Moamonin took a big risk writing that script.

RS Some of it is the HMOs too because Jennifer has one of the top neurologist in the city and also surgeon. you know when we were with Gen Care they just kinda tied his hands and he was frustrated and when I got them out of the picture. you know they were like lets go to work on it. So you know sometimes doctors are willing but you'd be surprised the threats they get from these HMOs. Some of these HMO can drop these specialists just because they recommend a certain type of device that might cost a few thousand dollars. That kinda tragic and I mean I don't want to get to talking about it that's another group therapy.

SH Yeah, Michelle your doctor that your talking about is an otolaryngologist so it's an ear, nose and throat doctor and I think probably they're different specialist and they know different things too.

M They always trying to find something for Devon.

DB Actually, I think my doctors are looking more at me. What do you want? What do you want to do type of thing? What is it your here for? You know, it seems like they're look at me for answers and I'm going to them for answers and we just seem to be getting no where. I've been to more pediatricians and neurologists getting second, third and forth opinions because no one is telling me anything that I didn't already know.

M I was just blessed because Devon had-- I met Dr. Hordaway when he was about six weeks old and when he was in the hospital I used to see him go and I always wondered why is he making that noise, he don't have a cold and finally by going back and forth to the hospital and back and forth the pediatrician finally they kept saying maybe he got tracheomalacia. I'm like what's tracheomalacia and then about 2 1/2 months he got croup and he started re-tracking really bad and took him to the doctor and he said take him to Children's. I brought him up to Children's and they had him on seventh or eight floor and they took him back to give him an IV and he started, he passed out. Hey, Devon wake up finally my sitter got him to wake up. They told me they were going to put him in the unit. He got better and said bring him back so they could do a bronch. I'm okay, and I did it. I'm just looked one day my the diaper bag and I saw this number and I called. They say oh, Miss , it's you. I'm like yeah it's me. We're glad you called and I finally called and made the appointment. The bronch him and they immediately told me Devon needs surgery or he'll die. I was like

SP What a way to find out

M you know, he needs surgery or he'll die? I'm like what for, why, and then they told me he had a narrow airway and he had no granulation to hold his windpipe. So they did the surgery and he's doing much better now.

SH Okay

M His pediatrician knows the surgeon because Dr. used to be the chief of pediatrics upstairs on the seventh floor. So all these doctors kinda work together and know each other. So I've been pretty good in the professional field with the doctors.

SP I want to ask a question of you. From you inside point of view, how do you feel about the relationship and the cross of information between doctors to the therapists.

SH It's very variable depending upon the doctor.

RS That's true, it depends on the specialist you know because I've been back and forth between two hospitals and I've kinda gained a repetition you know but I don't particularly care because I'm not running for president so I'll offend somebody if they're offending my child. I had a brain surgeon tell me one time, he said well I'm under certain limitations and I can do this you know and I'm skilled and you know I've been doing this thirty years. I said well, I've had so many patience and I just looked at him point blank and I said well Jennifer is not one of them any more. Your off her case. He was like What? I'm like we're all on the same page or whoever is not gets off. That's the way I look at it. If they get offended tough.

SH Shelly, I'm just going to get back to the question for you so you can get it in your mind. What has been your greatest concerns in working with professionals in actually getting your child's AAC device?

SN Well, I'm going to be the bad guy and I have to exclude you because you never really worked with Tommy before.

SH No, I just saw him the one time.

SN But I think that speech pathologist are the worst, and the hardest because maybe because that's Tommy's' worst area you know of course, but um we need to keep it in consideration all of his occupational problems and all of his physical problems. We're trying to find a kindergarten room to place him in and the speech pathologist are just pushing us. He needs speech and language. He needs that's gonna.. he has cerebral palsy we can't just stick him in speech and language you know I just found out yesterday that his time is going to run out on his device next week. I just found this out yesterday. So, after next week, his time on this device at school is going to end, so if it takes me three months to get this device, we're going to start all over again. He's really excited about the machine. When I come to his school, he gets it and he points to it. Even the day we were here and the machine really didn't do anything, he was pressing buttons and really insisted in it. I think that I've had better luck with physical and occupational therapist working with his speech delay than I have working with his speech pa that's been several of them.

SH What do you think the role of professionals should be when trying to work with you to get your child's device. What do you think they should do? What should be do in helping you get that device? Riva your ready to talk.

RS I sure am. I have, I can say that this staff here of speech pathologist is one of the best groups that I have ever seen and I'm blessed in the referrals that I have in my home come through an organization that works with Children's Hospital. So I'm blessed, but working with some in ???Wrecking Jordan??? and it's a wonderful place, but I met this really strange one, one time. If you can not communicate with a person and a person is locked into something and somebody know this individual all of their life you can not eliminate that person from the evaluation process. I think that is the most backwards way of thinking. I don't care if you've been in school 20 years, if that, if this is her father or his father and his mother and they say my child is doing such and such you owe it to that child to take that information, use it and in your evaluation. I don't care if you didn't go to school for it, it's worth that child, that's his chance and when ever I run into speech therapist that do that kind of stuff and their are some of them out there and I don't know why they do that. They have this clinical mind set and they say well that's just mom saying that or that's just dad. We don't' you know.

SN If they don't test in certain areas.

RS Right

SN Tommy just went through testing and you know when we got done with that testing. He didn't do it. You know learning disabled, useless, I mean it was awful.

RS exactly, exactly

SP They miss a lot of hidden intelligence

SN Oh yeah, and tit's awful and this is someone who has never met him before. She works at special school district. She walks right in and test him and you know and that's not a true evaluation.

RS It's not a fair evaluation and you've got to be careful with that kind of stuff because insurance companies look at that and holds Children's back. They will not pay for the Alpha Talker based on someone doing an evaluation like that.

SH So what your saying Riva is that you know professionals- what you wish they would do is to consider the family, include the family

RS more

SH include the family in the assessment more and really value their opinions

SN Or really try, you have to know the child for a while.

RS exactly

SN You can't just come in one day, test them, and make your evaluation. I don't think that's fair.

RS That's right, that's right

M Because kids all shy away from what you want them to do because you be telling Devon to do sign language and he won't do it but you know he knows how to do it, yet he may five minutes later do it so you can't just go in and basically think that the child do it.

RS And you know

SN I think that they should let the therapist be therapist and have one person work with insurance companies. That's what you really need because I don't think that the therapist has the time.

RS And they get a little scared, some of them when they are doing their evaluations. They get a little, when the HMO calls them up and all of the sudden they're like hey, move on to another therapist. I mean that's what you have to do. I think that's really tragic and I've ran into that too much when you get to using a lot of expensive equipment I think which is um cast aside you see I just developed this mentally now where if you don't deal with me then you don't deal with Jennifer. That's just the way it is.

SH Debra, do you have any idea of what you think the role of professionals should be when trying to work with you in trying to get an AAC device.

DB To actually get it, actually I don't have a whole lot. My actual evaluation and the process to get it I think everyone has done everything that they could do to actually get the device. um so I mean from what I've been through the experiences I think everybody done everything that they could possibility do and I don't have anything.

SH You don't have any advice for them?

DB No

SH Shawn

SP I'd agree with what she said. I think that I'm willing to do a lot of hard work for my daughter but a lot of time I wouldn't know what to do. I could just be talking in circle or walking in circles but if I could get the information I need from professionals telling me this is where I call. This is where I'm gonna get the evaluation I need to get. This is all I need but I need as much information as possible.

SH The next question kinda follows.. What things about AAC devices that were important to you were not considered by professionals. Do you think that there were some things that professionals didn't consider when they were looking at AAC devices with you child? Riva

RS Not me, I was lucky. They did a great evaluation on her, they knew she had been mistreated by the HMO and they just stepped in and said enough already. Let's give her what she needs, this hospital did. I don't have any complaints believe it or not.

SH Shelly?

SN Time frames are kinda, but that might, maybe like when we came here for the evaluation we didn't have any idea how long it was going to take to approve it. I was thinking when we came you know when he went into his IEP the next week, we were gonna kinda know yea, or neigh and I'm still kinda hanging and that drives you nutty.

SH So time frame is a big thing.

RS Oh yeah they do take a while

SN Or just let you know when you come in that it isn't going to be... it might be one or two months before you actually get approval and

RS I just want to say.. this is pretty critical that when your renting a device you should really work closely with the family when your renting them because it can if you miss something it can, you an lose time concentrating on certain type of switch if you don't have the family input. For example, when we were working on a certain kind of switch with Jennifer and we didn't realize that the reason Jennifer wasn't interested in these switches was because they were boring colors to her because of how brain damaged people process color. So the therapist went in and painted it electric hot link and red and now she uses it. So something that simple changed her evaluation and speeded her up. So I think that you got be careful, you got include every aspect of it when your under two months deadline on rental you need to explore everything. So you could really cheat a child of a piece of equipment cause of that so you know we almost said you know this switch doesn't work. We came that close to just ruling it out.

SP Well, in their situation, you said you were going to be losing the device briefly. I know with Kayla if she goes to summers sessions at school and all of that because if she misses out on education she'll slide backwards. She lose what she's already got and you'd just be wasting your time then if you lose the device for a while after you have already been approved. There should be an overlap of some sort.

SN None. Then they told me yesterday, that they weren't going to write it into his IEP because then they would be responsibly for them having it in the classroom. I thought you directed towards

RS I would fight that

TN Well, we

SN Oh yeah, we have another IEP next week. We're just think you know I

RS I give the school moody blues about stuff like that because you know when we started therapy with Jennifer they gave me all this stuff. we're not going to potty train her. We're not going to.. I said oh yes you are. If you want to get rid of me you are. So we sat down and we worked it out. So from now on if you don't want to see me out here then we're going to have to talk about this because this is my daughter's life you know what might not be important to you cause of your policy if your son needs this device to communicate and make his quality of life better then it's their job to give it to you.

SN I told the thing that I think Special School kinda got their toes stepped on ??Monaviddi?? sent us and said that I think Children's might be able to do it a little bit quicker because special school has a certain time frame. So I think maybe they ... maybe she's getting back at me by saying well next week times up you know.

RS You know so therapist have egos like that. If a group of specialist in one place in helping you child they tend to get to where well, we're not participating in that. Well, when I had my IEP meeting I had the team there. I brought the team from home there and we made them aware that this team here was working on it. I said this is how it's going to be if Jennifer, if we don't all pull together and help my child and we're not all on the same page then I'm going to have to sound the board of education period. That's it.

SN I think Tom and I are very realistic people. We don't try and pretend like everything is rosy and we don't like to hear things. We know what we're up against and um it's hard.

SP Maybe be just be front with the time factor right off the bat.

RS exactly

SP So we don't think that we'll have it tomorrow.

RS Exactly

SP When we walked in we didn't know either. You guys were real good about letting us more of what it was going to take.

SH Debra do you have some thoughts about?

DB Actually, I kinda forgot what the question was?

SH Okay, I can take in like what things about AAC devices that were important to you were not considered professionals.

BD Actually, about the only thing that I would really advise anybody that is really wrong to do is to give the child a device and take it away. Like they're saying is happening their shoes. My situation with the Dynavox, it's the time frame with the new model was really, messed us up a lot, but what happened is and if I had it to do over again I would definitely change it. We had the rental period for three weeks and now three months later my son is going to get the device. Well, what I should have done is said keep your rental unit until the month before he gets his device. If I had it to do over again. I would definitely would. It is wrong to give a kid a way to communicate and take it away from them. I don't care what it takes you either don't give it to them at all. You don't give a child a way to communicate and then take it way. In my case the first week, I thought this is not going to work. This isn't for him. He took to that thing so fast that I was, the last several days I literally put it away and it just sat there because I could see that he would look for it. He was starting to look for it when we would leave he would like go to the table and say hey, you forgot something or even when we finally returned it to the rep. When we went to leave he reached up on the table and wanted to take it with him, so my biggest thing would be don't give the kid any thing at all unless he's gonna have it forever or whatever. Don't give them anything and then take it away from them that's wrong.

RS I'm going to state this and then I'll be quiet. You know you really shouldn't hold a communicate device after you do the evaluation because they cause dangerous medical problems with children. Like, with my daughter, since she has a fracture in her wrist, we're literally working all this out so she can use this switch. Now, that's a new skill for her. It's a motor skill, if you take it away for three months, she's gonna lose that ability. The second thing is that with brain damage and some of the other injuries or things that children are born with it, it's a learned pattern of behavior. You can't take a child and put them in front of something and clinically put him in that position and then take that pattern away. He's got to be re-evaluated, re-programmed and who's to say that a child with a deficit will ever acquire that again. So your taking a big risk doing that.

SN He uses his box. Tommy uses his box to recall the at the end of the day they have re-call and they're encouraging him to use his device, his Delta Talker at re-call. So when he comes back from spring break, you know, he's gonna what to know, how's he gonna feel when he's sitting in that circle and he's been able to communicate

RS Frustrated

SN Yeah.

SP ostracize a kid

RS That's not fair to him

SN Then give it to another child. I guess there's like a three moth period, they get it at school.

DB It belongs to the school and they have to share it with all of the kids.

RS But that cheats all of them.

SN But, if we would have know that we would have had the insurance company three months ago

SP The way I see it, the child's psychological set up. That's their voice you know. I have a son that's in to everything and he's going to want to play with it That will be off limits to him because that's gonna be Kayla's voice not a toy. It's not gonna be a toy around the house.

SN Yeah, I was wondering about that, like kids being really interested and wanting to play with it. How do you do that? How do you.. You don't want to make them scared of it or anything. I guess that's another group too.

SP The training.

M My kids are older, so they'll probably just try to help Devon.

SN is a boss, she'll probably She carrier a Kleenex around and wipes his chin if he drools, so I'm sure she'll be teaching him how to use this.

SH Okay, here's your chance, if you could tell professionals how to better work with families when trying to identify AAC devices for children what would you say? If you could give some advice about how to better work with families?

SN The same thing: time frames, if it doesn't work this is where we're gonna have to go and this is how long it might take after that.

SH Then really stress the time frame.

SN What to do with the Intro if it gets taken away, what do you do, what replaces that or how do you rent one.

SH Anybody else have something....okay, how to do thing if at all are the values or beliefs of professionals different from yours and if so how did these differences affect you when decisions are being made about AAC devices. Do you think some of the people working with your child had like different values or beliefs and did that affect at all the choices that were made about the device. Shelly you shaking your head.

SN Really everybody wants him to have it, but like who's going to do the work you know?

SP A lot of it is probably just political stuff.

SN Everybody wants him to have it but they got it for him and now everybody kinda stuck.

TN I think a lot of it's the same thing that everyone's gone through, not just with the AAC device, but with every aspect where people, there's just so much out there and it's impossible for every specialist and therapist to know. It's enough to know exactly what they're doing everyday and working with the kids and but what's on the fringe is of what they're working on that might be able to expand and overlap into other areas. It's difficult for the professional to know everything that's going on out there and things aren't, naturally insurance companies aren't real cooperative letting everyone know what's going on out there. It's, it's there doesn't seem to be enough, um management type people who in therapy organizations and Doctors offices who are kinda like gate keepers to all the knowledge of what going on, what you know. You have the salesman come in and if the Doctor has time to see this salesman which most of them don't then he'll see him or the therapist, but there aren't enough office management type people and gate keepers for all of the information that exists out there and all the research that companies are doing. It's too much is put onto the actual therapist and on to the Doctors and you know, you have therapist and doctors and you may have two ladies running, doing the billing and filing in the office and there's no business management in like you know rather large child therapy areas and therapist are responsible for doing all that and there should be more gatekeepers to help sit down with the parents and worry about the business part of it more that the actual working with the children making then aware.

SN I just told Debra before it started that you know if you have a disabled child somebody should just fall at your feet and say you do enough everyday just waking up and getting them to school you know much less everyday. Debra says everyday we write a letter, we make a phone call, everyday in addition to raising a kid that already difficult.

SP It's not easy.

SH Okay, Has anyone run into problems with feeling like the professionals working with their kids have like a different set of values or beliefs than what yours are and that's affected..

RS I did before I met you guys. I did before I came to children's. I mean I've met, I was in a strange situation. I met the chief physical therapist (tape ended) We have to be careful. Everybody's trained and a lot of these people go to school, spend their lives in clinician situations but there are some people in the system who do not get exposed or who don't have the ability to get exposed cause of insurance companies and doctors and gatekeeper types of situations, but you know. Since I've been at Children's, it's different here and I'm blessed, but I tell you if you ever get in a situation where a therapist does know anything and doesn't keep with the latest of everything that's a dangerous thing.

SH Just gonna talk a little bit again, getting back to the family about roles and I know like some of the children have brothers and sisters and siblings and parents of course. Some children are very passive and some children are expressive and maybe even if they're not speaking. Do you see the communication devices as affecting the roles, Their role in the family or your role. Do you see things changing there? Michelle, you sorta indicated that Devon was pretty expressive, he

M Yeah, he's pretty expressive. He can tell you what he wants.

SH Do you think it will be helpful in like, or do you think he'll become more outgoing or about the same?

M I think he'll be more outgoing because he'll be able to talk instead of just making noise. Then I think my daughter too, she'll be overwhelmed cause I know one time he got sick and we could hear him cry. She said mommy I haven't heard him cry since he was a baby and then she just literally started crying. She said, listen, listen, you can hear him. But I'm like your not supposed to hear him. He's turning blue. She was crying and I was trying to bag him and so I think that when he starts talking she'll be able to hear him or he'll be able to hear himself. I will too.

SH Does some of like his brothers and sisters do they try and speak for him do you think? Do they try to interpret what he is saying or do you get that? Shawn's nodding yes.

M No, I guess Devon is still small. He's just, he'll be three in May and other than when he used, no because he's not even mimicking words yet. He just goes (makes sound) and you just be like wonder what he's saying. You know talking on the phone (makes sound) still you don't know because he's not mimicking words or anything. He just does some sign language stuff- basic needs like what to eat and drink and girl or happy or some I don't know.

SH Shawn your kinda nodding your head yes.

SP I got a strange situation. I got ...Kayla, she six years old and she hasn't ever talked. I have a four year old son. If he's awake he's talking um and he's a big help with Kayla cause he knows what she wants. If he's getting a cookie he'll ask for one for Kayla. You know always taking on the extra responsibility and sometimes it's kinda annoying. I love him to death but if he's awake he's talking and

SN I think just cause, like if and when you have one that doesn't talk

SP I think he's making up for it

SN Yeah, and your not used to hearing it because we think the same thing. It's like Danielle shut up you know. She doesn't necessarily talk for him, but I guess she think she know he's not going to sit down and have a conversation with you so if you ask a question to the both of them here she goes. She thinks it's her responsibility to answer.

SP I think it's gonna change his outlook on things. We had a Barney doll, you pull the string and it talks. Well, it broke um and we threw it aside and one day he came up to me and said, Dad Kayla's broken isn't she. Well hopefully this communication device will fix Kayla and I think it's going to have a profound effect on him because he's always been, he's two years younger than she is, but he's always been the older brother and I think he's going to have to learn to give and take a little bit.

SH So you can kinda see maybe she'll be able to speak for herself some and

SP I think it's gonna be a neat transitional phase.

SH Riva and Debra your children don't have siblings is that right? So I guess the only roles, is do you think your roles will change in the family. You'll still be the mother, but can you see your child being more assertive

DB Definitely more demanding, I think once he figures out that when he says what that the machine is going to talk for him and when he make it talk he's gonna get a response out of me. I think I'm gonna be running myself ragged trying to keep him happy just so thrilled that me can actually tell me something. Especially since he's an only child. There's not much that he doesn't get anyway and as far as my attention goes, there is no one else so and he knows how to get my attention now. If there's something that he wants bad enough so actually I think he'll turn into a demanding kid I think.

SP That will make up for lost time.

DB Everyone tells me that he's gonna make up for it.

SN I think it will be nice to just talk um like have a conversation not just out a necessity and need. You know basically that's all. You know Tommy, last week we were amazed um he said something about Dr. Suess they week before it was Dr. Suess's birthday at school. We've never heard him re-call something from a week ago. He doesn't just talk to be talking. It's just what he needs or what he wants, or if he hurts.

SP It will be an asset to the relationship

DB I think that will be pretty neat living by myself you know the phone is the only conversation I mean I work part-time so I do get out of the house I little bit but, you know it just the noise of having somebody else to talk to driving down the road or everything, just to have somebody else to talk to actually a little five year old conversation would do me a lot of good right about now. So it should be, I'm looking forward to it.

SH Rivas got a lot of people in her house to talk to usually, so you don't have to worry about that one. You used too (referring to Michelle)

M I used to have a lot of nurses

SN Do you think being therapist like experience with these that our expectations are to high?

SH I'm totally impartial. I think that I think you feel fear to express whatever you don't be afraid to said anything because I 'm a therapist because I you need to educate therapist. You need to educate professionals of what you have to say is really important. You know your family members and if your not being considered by professionals or whoever you know you need to tell us so that we can hear it.

RS I don't you know but just on that from my situation having to change system for my daughter. I don't think that your expectation are too high because you're your sons parents and I think that therapist have to, like a therapist told me one time who is very qualified. She said that if I get a kid and I'm not doing what's needed for that child to progress and there's another therapist who has much more clinical and technical experience then I will recommend that child move on to that therapist and they you know all of them should view it that way and just cause a parent has high expectations the only way that um a parent should be told well that impossible for your kid to do is if somebody has medically proven that without a doubt. Unless they have done that then they're being unfair. So I don't think that you can demand to much of a therapist I mean if it can not clinically and medically be done that's one thing you know. But when they started attacking me with all that stuff I just left them.

SP We've already gone past most of the mile stones that the doctors have said you know.

RS Exactly, exactly

SP So you gotta

RS I think it's a good thing for all parents to have high goals. I think that some therapist need to get out of the mind set of when we have high goals you know the reason I'm so sick of hearing that word denial. You know I 'm like is that something you wake up and sang. Did somebody teach you that when you got ready to go into therapy school. Denial- I'm denying that your driving me crazy saying that. You know I know what's wrong with my daughter, so I think we beat that word to death. You know I just tell professionals use any word you want but don't use that word on me. Cause we're not in denial, I mean you know how you sons condition is and your trying to help them and I know where my daughter's at. We, it's our duty to give them the best quality of life they can get you know if that's to high of set of goals some professional looks at them. We've got the wrong professional and that's what I think.

SH Okay, I've got one more for you. I want you to think about yourself and do you think that having a device will affect your relationship with others particularly in the community. Okay, not your child, but your relationship with others do you think that's going to change in the community. Shelly?

SN Oh yeah, I'm going to be know as super mom. She's got his device and him and you know I do think that I'm ready, that if you do everything you can for your child that people respect you know and I think it's going to be a lot easier for me to instead of if he's carrying a box people are going to think look at her. He looks perfectly normal you know he smiles, runs, jumps so people who are see him when they talk to him they are like or if he tries to talk to you oh god then your like so if he's got that box then it's going to cue people right away. Then it's going to be a little bit easier, on me too.

SP Less explanation

SN Yeah, you just feel like, if somebody says a word to him you have to go into your explanation. Like more so

SP medical class

SN yeah

SH Debra, do you think it's going to affect your relationships?

DB Oh, I'm sure it will I'm sure it will just myself alone it already has um yeah, cause don't get me on my soap box cause I'll tell ya. You'll go oh. No, just pretty much um educating people, most people so far that I bother spending anytime with are most interested and they want to hear what we have to say or what you've gone through and stuff and I would just, just helping other people. I'd do anything to help someone else who's already, who's in my shoes. If I would have had somebody guide me and help me, boy I would have though that was great. I would love to help somebody else along. Just helping other people and telling other people what I've been through the respect that you know that people give you for doing what you've for done for your kid or whatever um you know friends too. You really learn who your friends are.

SH Okay, Riva do you think having that device is gonna affect your relationship with others in the community. I don't think, not in my community. I think everybody in my neighborhood knows about Jenny and they all love her and they are attached to her. The people on my block they're all retired and they all have adopted her. You would just think she gets, they're just overwhelmed. You know, it just kinda goes around the block, Jenny's got this you know. It won't bother my community situation. What it will do, it will affect her environment when she goes to school. My IEP goal is, they say what is your goal with your communication device with your child, if my child is ever threatened or in trouble I would like for her to be able to ask for help. So say this person is treating me unfairly. That's my biggest fear for her, that she won't be able to defend herself in any type of way, even verbally, but I you know

SH Anybody else think that it will affect their relationship with others in the community.

SP It has already mine. I don't have it yet, but a lot of the people I work with and the people I know are kinda unaware of the situation I'm having with my daughter. I was just at the copy machine at work making photocopies of the Delta Talker and stuff. They're like what's that and I tell them and they're like that's really great. So I think it will.

DB What the devices cost blows people's mind. I ran around with a picture at work one day of what my son was gonna get you know and stuff. They're like just in conversation you tell them what things like this cost. It blows their mind. They can't believe what it costs. It wakes a lot of people up to what the response is that families with kids with problems go through. They actually have not the foggiest and just and then they're like your gonna send that to school with him what are you going to handcuff it to him. You know because I have the issue of who's responsible for this thing if I put it on the bus one day and he comes home and it's not on the bus. No one wants to be responsible for that and n one will give me any answers. Just that the cost of that- these devices alone it overwhelms people. They don't have the foggiest idea of what things like that cost and how are you paying for it and you know they're really interested and stuff and you know how you and how families-- families really can't afford them at all but who and when the insurance companies won't pay for them and all that kind of thing.

SN Can you insure them or do you is that something that you should do I never even thought about that until you

DB Actually through the school no one wants to say. I called the principal, she says oh I don't know what to tell you. We have lots of them here and it's never happened you know she won't give me an answer as to who's responsible and then of course I call the bus company and of course they tell me the same thing and um homeowners insurance that since it's a like a portable device it's not covered on your regular homeowners. Your supposed to take an extra writer out on it and all these things. So like I was real nervous about, I am nervous taking this thing back and forth to school cause I can't afford to pay for a new one if it disappears and I have had little things disappear on the bus many, many times and so it's been a concern for me just putting it back and forth on the bus. I mean you know if anyone really knew what they things cost like the driver boy, would they tempted. You like to think that they would not be but when people realize how much they cost it's gotta be tempting in a way I guess. I don't know, but no one wants to be responsible for the theft or anything of them. If it's in your car and your car gets stolen, you think the insurance company is going to believe that you had that kind of device in your car that's really worth that much. No one wants to be responsible for it.

SP Maybe the companies that produce the devices can look into and find out what type of underwriting they could get. I know when I bought a cell phone they told me when I bought the phone for this amount of money we'll insure it. You know so they would have more resources on hand trying t locate something like that. I don't know. I never really though about something like that getting stolen. It would be hard to replace.

DB And then you'd have to wait on the waiting list all over again. That's the torture.

SP Get the little car alarm on it.

DB I've had people tease me, maybe we could just little bitty handcuff and just cuff it to him. Well, I don't know.

SH Michelle what about you? Do you think that if Devon gets a device it's gonna affect your relationship with other people in your community? Can you see any change or

M Well, no not really cause he probably won't take it out.

SH He'll probably keep it at home?

M right, probably keep it inside the house unless, I may take it over to my mothers but in the community when he's outside playing with kids- They all know he can't talk so he'll go (makes noise) they all go Devon, Devon

SH Okay, well the last question I get to ask you- Is there anything else about this subject that I haven't asked you about? Is there anything else that you would like to talk about in relation to communication devices and families, something that we haven't considered tonight that you thinks important that you would like to bring up. Go ahead Michelle, anything?

M I think that it's important that the nurses when your child comes to the hospital that someone up on the floor know how to use the device or knows how to do sign language cause Devon had a little boy in his room last year that had a trach and no one upstairs knew what he was saying or anything and I was so mad. You know cause that could be my baby and I was trying like please come over here and help this baby. It was a big boy. He had been in an accident, I guess he was like 14-15 years old, but my him being in an accident, he was kinda, he knew sign language and he was able to talk. I mean he was able to walk and everything but he still had a trach and he couldn't communicate that well. I don't know what was wrong with him, and the nurses are all going I don't know what's wrong with him, get a doctor, get somebody and I was literally crying cause I was thinking if you don't know what's going on with this baby how can you help my baby who's even younger than him. I think someone up on the seventh and eighth floor needs to be trained on how to communicate with the kids who can't talk.

SP Well, I don't have any experience with devices that you can make the best possible devices but without support services they're not worth anything so that's I'm not saying that's going to be problem but it needs to be a priority I think.

DB I think one thing that I'm afraid is going to happen with my son is his motor skills are real, real, delayed too. I want him to learn signs also and I already see the teachers and the therapist at school since he understands that they drop signs with him and he has not acquired any new signs in a very long time and I think that the device is going to be so easy and I don't I don't think he gonna, it's gonna be a real issue for me to make sure that me stills learns sings. I want him to know signs. I don't want, if the thing does disappear tomorrow or breaks down or whatever to be without I think it's real important that they do use signs and I think that these devices could easily do away with signs unless you know, they parents or whatever made it an issue.

SN What happens if it does break? I mean is there

SP 1-800- Delta

SN Is there Delta centers around?

SP I don't know

SH It depends on your device and the company.

SN Yeah, you know I think a day without it. It's pretty would be when you get used to it.

SH Those are all issues you should bring up. I think you've brought up some really good ones that you know the transportation problem to and from school, and the fact of do you insure the device, what happens when it breaks down because they don't last forever. It's like everything, your VCR, you TV everything breaks down.

DB Especially computers, the one that my son is getting is so new that there has already been glitches in it and I'm thinking okay one day this thing is going to not work. The software gonna go crazy and then whatever, because that's what it is. It's a computer and whatever

SP It's like she said about her son wanting to learn sign language anyway. Couldn't the device be used to teach, have an overlay with A and then the sign for A. Do they have something like that?

SH Actually there is one company that has one that has the finger spelling on it.

SP That's a great idea.

SH Anybody else, it's your chance if you want to speak up, otherwise

RS I just, naturally I have something to say

SH Go ahead Riva

RS You can tell I get to a lot of seminars. I'm sorry well, I just think one thing- you said do we have anything to say directly to professionals. I think that all professionals and I've encountered in Children's which is good should realize that parents are your greatest resource and with the trouble the medical system is in now if you use us and train us we can literally save you thousands of dollars and you have to understand that the trouble the system is in now that could be used for another child's life and the fact that you are not tapping and not everybody's doing that some of the big hospital networks and equipment supply companies you know who supply certain types of devices they are not doing that. When you do that you literally waste thousands of dollars. This mother says that his particular devices works for her son and she wants it you waste time and energy sending her a piece of equipment that she can't use. There's a another child over there on that waiting list, waiting for that device who's doing nothing so if you if you tap into the resource you cut down on what's going on through out and u I think that something that pretty soon we'll gonna have to look in the mirror and face that if your gonna throw people out of the hospital and HMO is gonna shorter the time and then you gotta educate the parents and your gonna let them play a stronger role and I mean there's no room in ego when you have a medical system in trouble like ours you can't say well I've been in school, I specialized or whatever to someone who you have said I'm not gonna let your child stay in this hospital six months, you've gotta take them home. When you put them in a situations like that there is no room for ego. You have to work with them that's your resource and you literally waste money and time and people's lives when it's not done. I'm gonna get off my soap box.

SH Anybody else want to say anything, any final words

SP Speeding up what she was saying that I don't know what capacity this thing we're doing today is going to be use for the device companies maybe they should take into consideration using parents in research and development. you now people who are using the devices instead of a couple of engineers in labs coats.

RS That's right

SP No offense because that's what I do

SH Well, we're almost on time we're doing pretty well here. The only other thing that I was going to ask people was if anyone would be willing to be contacted by a phone call like maybe several months after this group.

No one minds

Focus Group of Families with AAC Devices

April 4, 1996

Debra Reichert Hoge, Ed.D., Moderator
Southern Illinois University-Edwardsville

Summary Background Information

Type of Group: Focus Group with families with devices; conducted by Dr. Debra Hoge, Southern Illinois University-Edwardsville

Date Conducted: 4/1/96

Where Conducted: Recording studio at Southern Illinois University-Edwardsville

Number of Persons Present and Roles: Susan Walter, mother of a 13-year-old daughter with cerebral palsy who uses a Macintosh laptop with KN:NX on board; **Angie Hillskamp**, mother of a 10-year-old child with cerebral palsy who uses an Intro Talker.

Logistical Issues: Arranging a mutually satisfactory time for all families to be present was problematic; inhibited full participation by all families contacted and invited to participate.

Modifications Required in Protocol: None

Synthesis Statements

1. Family Concepts in Working with Professionals
   - Parents want ideas to be valued
   - Parents want concerns to be validated
   - Parents want to be included in meetings
   - Parents want new team members to be familiar with past work of team
   - Parents want professionals to communicate their concerns
   - Parents want professionals knowledgeable about AAC to perform AAC responsibilities
   - Families must independently identify resources in state and community, but are not acknowledged for these efforts

2. AAC impact on Families
   - Children with physical disabilities may have difficulty with scanning features
   - Family member may need to be present for child to be able to use AAC devices
   - Use of devices requires time commitment by family

- Integrating devices into family routines and maintaining quality of life may be difficult
- Families have concerns about social uses of AAC while professionals focus on academic usage

3. Relationships with Community
   - People in community may be fearful of AAC
   - Attention is drawn to child and family in public settings
   - Use of school-owned property in public settings raises concerns regarding breakage
   - Families don't know what language child would use in community settings
   - Limited programmed language may inhibit sustained communication interactions
   - People may not understand how to maintain conversations with AAC user
   - Pubescent children want to be independent yet have limited vocabulary repertoire
   - Family may limit AAC usage if child doesn't understand pragmatic rules

4. Changing Expectations
   - Perceptions before and after AAC device delivery change
   - Devices require more time/responsibilities

5. Funding
   - Families have multiple responsibilities related to funding:
     1. identifying resources
     2. participating in application process
     3. waiting for receipt of device
     4. learning if device will help child
   - School personnel don't want families to be aware of school obligation to fund assistive technology
   - Family may be reluctant to take device out into community if they are responsible for funding
   - Family assumption of responsibility to ask for AAC funding in community generates stress
   - Team approach for shared funding responsibility is necessary
   - Community may perceive family lifestyle to be linked to ability to pay for devices
   - Funding process involves some guesswork and uncertainty regarding whether or not devices will work
   - Funding sources in community will have different value systems from family which drives funding decisions

6. AAC Decision-Making
   - Professionals need training in AAC to effectively work with families
   - Child preferences differ from adult preferences for devices
   - Family preferences for AAC must be valued

- Professional recommendations are based on short-term contact with child (versus lifetime contact of family)
- Children with similar symptoms are unique individuals from different families
- Desires and interests of child must be considered
- Professionals must consider age-appropriateness of recommendations
- Professionals must recognize that children are not infants if unable to talk
- Professionals must recognize child's need for "personal space" during AAC interventions

7. AAC and Community
   - Persons in community may treat child with AAC device with more respect after receipt of device
   - Persons in community have difficulty seeing beyond child's inability to communicate.

8. AAC and Family
   - Extended family members have fears/misconceptions of child w/disability

9. AAC and Teaming
   - Families want to feel like equals in team decision-making
   - Families want to lead role on teams to change to be sensitive to changes in family routines/needs
   - Trust in team members is essential
   - Professionals project their perceptions that families are in "denial"
   - Family sees long-term commitment to child while professionals see child in a limited time frame

Transcript

DH: Intro and ground rules. Why don't we jump right in to one that Sue thought she was interested in. It was an idea about what your greatest concerns in working with professionals in getting your child's device was. This will be good information for those of us that are helping people in training.

SW: Well, first of all, one of my concerns in starting out was that obviously that they would listen to my ideas and that they was validate my concerns and include me when they were having meeting and having discussions. So that I could tell them the kind of things that I felt Jennifer liked and didn't like and the kind of things that I felt would work at home and that we could manage at home. That was real important to me and I was real concerned that would happen. Then also one of the things that we did experience was professionals changing during the course of our work together, and then new people coming on board who weren't familiar and how to do we all be on the same page and so that was really and that is a big concern. It was a challenge for us to make sure that we were always on the same page. It did cause some, not big problems, but it caused unconfortableness at different times, when if a new person would come on board and not realize where we were. There were positive benefits too, cause they might have good ideas. It is a concern if different people get involved and then you have to, as a parent you feel like you have to start all over again. Explaining your family situation. Explaining everything about your child. Explaining everything about your family. So your just feel like your having to bring people to speed over and over and over again.

DH Like da ja vu?

SW right, so that's a concern

DH Any concerns Angie?

AH Also a concern of mine was if they didn't agree with the parent. You know it was like- how do you let them know that your concerns, that you understood the child and felt like they should be paying more attention to what you were, what you were

DH What your concerns were in addition to that. Okay, those are real big issues and that's probably even bigger than just augmentative. Those probably issues with assistive tech and schooling

SW It goes across the board

DH Anything else- concerns- in terms of professionals?

SW I think one of the things that we experienced also in the very beginning when Jennifer was much younger and we first talked about having our very first device was like people. I guess what they did in the beginning was they had speech therapist and OTs and PTs who were already had full loads trying to, they didn't want to hire new people just for technology so they were trying to get these people to do that in addition to their other jobs. So these people, which I could understand I was not empathetic to their situation where they already have a full case load of kids to give therapy to and now their being told you need to learn how to use these devices or you need to find where they are so we can experiment with them. Those people were stressed which made us feel stressed.

AH A lot of these devices were new to them anyway because their not familiar with this background and so it was hard to teach them.

SW Living in a small community with not as great of resources

DH And even with the age of your girls because one's 10 and one's 12. So you all have been at this for a while, it's not like people who have little teeny ones now that you've got Rochelle Cox or an expert who comes out and says this is the hottest thing. I know what to do with it.

SW Like in my situation, I spent one whole summer doing the research, like calling Springfield to and 800 number finding out where is all, who are all of the technology experts in Missouri and Illinois. How close are they to me and how do I access them. That's how I found Rochelle at Easter Seals in St. Louis. But I did all of the leg work for that, which is fine, but then I had to fight to get them to listen to me and say and know you I found an expert let's bring her in. They're saying well, we don't know her and she's not from our area or that might be expense and you know, so those kinds of challenges.

DH Who does, just thinking about the effect on your family now that you've both got a device. Let's talk a little bit about organization of the family and some of those questions come down to things like who's in charge of programming? Who's in charge of maintaining and charging things up and selecting just. How does that affect your family with using the device. I'll give you some examples, when we had our professional group in here, ther were just some things that we really hadn't thought about, like families who were very religious and wanted to use up all of the memory on a device so that a child could say their prays. Just different issues like that about what to put on it. Angie brought up a point about not agreeing with professionals and their might be things that you want on your device as a family and you've got go to, fight with the professionals about that sort of thing or have some conflict resolution, I guess. If you all will talk about the ins and outs day in day out of the device, the effect on the family.

AH Well, Brookes' device stays at school when she's at school with her because we're still at the level where we don't have it down pat yet.

DH: What does she have?

AH She has an Intro Talker.

DH Oh, an Intro Talker

AH It's a scanning Intro Talker and see she does, it's really hard for her to hit that square.

DH: Does it have 32 little squares on it?

AH No, it has six or nine.

DH Okay, so they've got it down a little bit.

AH But because of her physical disability she doesn't have, it takes so much time. By the time she may want to hit a square it may be going to the next square.

DH As it's scanning along.

AH Even when we slow it down, it just takes so much time for her. So we're still at that level, but during the school year it stays at school with her so the speech pathologist does everything.

DH Plugs it in at night, does the programming, etc. Do you get to bring it home in the summer?

AH Yeah, then I get to do that.

DH So you get to do most of the input yourself.

AH Right

DH So she's had that device at least through a summer?

AH Oh yeah, she's had it at least five years now.

DH Okay, so she's had that for a while.

DH How about Jen? Sue

SW Well Jennifer has and we just, this is her third year I guess with a Macintosh lap top and then we have KN:NX on board. It comes home everyday. The school district purchased it. It is their property, but it comes homes everyday and on weekends and all during the summer. So we really have access to it all of the time. I-- if it needs to be plugged in or if the battery needs to be charged I do that at night. She does a lot of what she does is really related to school work. We've started in just some general communication things and we have met, I've really, they've really taken full responsibility for that. We still have, we have a technologist who, an assistive technologist who comes in as a consultant so he works on a lot of that kind of strategy. I am included in making those kids of decisions. So her device we use a lot for school work and I received the same kind of training so I know how to use it. I guess at our house the thing that might be a stressor in our family is that Jennifer, somebody has to be there with her and somebody. One evening I did walk away and she wanted to- I had a game in for her, it was, we were having a break. She wanted to do the game real bad and just physically, I mean she didn't do it on purpose, but she grabbed to pull it close to her and it fell on the floor and broke the lid. It was I mean it was a tragedy, major tragedy. My husband and my son know how to use a lap top, but they're not real familiar with using the KN:NX on board and have not felt real comfortable in getting for familiar. Which is fine. That's their choice, but then it all goes on me and sometime then all my time is taken up having to be with her and having to do it. Having to take the main responsibility and then the stress comes in when I don't have the time to commit to my other child when he's got homework issues or things to do so that becomes my main responsibility and it can get time consuming.

AH Not to mention everything else in the routine.

SW right, right, it can get real time consuming, DH with work and school

SW so figure out how to, well to convince professionals and then also to do for yourself. To try to figure out how to integrate into your life so that you feel like you still have a regular life.

AH A lot of times they tell you we need to do this, this, and this. Your like yeah.

DH how am I going to fit 28 hours in the day? When are we going to fit in everything else?

AH And you want to for the child's sake. You want to do whatever is best.

DH And that's only natural. What happens when your not home and the device is there and somebody want to communicate with the device?

SW It doesn't get used. Now, see Jennifer has enough speech

DH She is somewhat vocal

SW She's somewhat vocal and I actually think that having a communication device and having a way to express herself has encouraged her to speak even more. Just because she's had interactions and she is very motivated to do that also verbally. It's kinda like what they say with sign language, some people are afraid to use sign language because they won't speak, but really it can motivate them to speak. So she has enough speech to get by for daily living. She can talk about either sign or say if she wants to eat or go to the bathroom you know that kind of thing.

DH The basics

SW Right, it doesn't really get used to much. My husband has on occasion, but it doesn't get used a lot if I'm not there.

DH So your the primary person

AH She doesn't have any communication, so basically what's in the IntroTalker can stay programmed. So say the speech pathologist programs something in there. Something to do with the social studies class at school, now that'll stay programmed in there until their on to a different subject.

DH The she'll re-program?

AH Exactly, if she's at home, like through the summer and there's basic things in there about play time or whatever, it's not that big of a deal it doesn't get used, if I'm not there.

DH Okay, it just depends on the content. How about for social greetings? Like Jennifer can obviously say

SW But you know, I was just thinking about that. I think that the school personnel tend to be very, very focused on school. Doing school work, which is fine. It's very appropriate, but I think it's so highly focused on that. That they tend to feel that the social part of it is well, we're here to do academics and we don't have time for that. Which the day is very busy, I mean there just going boom, boom, boom from thing to the other from class to class to class but I do have concerns about the social aspects and should we be trying to take a little bit more time out for that because there again that does affect our family. Jennifer is 12 years old. When she was younger, you know, when the kids were all younger, ı think she did, she got a lot more invitations. Part of it is the age thing. She can't get around as well, but I think if they did a little bit more in terms of social communication, maybe kids would feel a little bit more comfortable inviting her to things. There are a lot of parties that she doesn't get invited to any more and part of that I think is communication. If she could express to them more her interests, but part of it is just kids because obviously the girls her age are interested in boys and you know.

DH But that content, again too. You've got, you've got, I talked with an augmentative specialist who had to put slang on the communicator for a child in junior high because the kid wouldn't use it otherwise. It's kinda like looking at the environment and seeing what would be real pertinent for her.

SW And she we're not, I think that we have some work to do in that area yet.

DH To just bring a child socially

AH I think a problem is too, is a lot of people don't know what to do. They're just kinda like, what can we, how can we include this in the social environment? What can we do? Where do we start?

DH The point about school not being a real social place, if you think about

SW It's a very social place

DH but from a communication point of view, you sit in your desk, you don't get to talk to each other. You know what I mean

AH recess and lunch

DH right, exactly recess and lunch. Even that venue would be something to program- some social information. Okay, thinking about, one of the aspects of this grant in addition to families in augmentative is culture. We're basically midwest, probably European American got some ties somewhere to Europe. You all are in a small community and one of the things that we wanted to talk about was community usage. Let me see how he put it. How does the augmentative device affect your relationship affect others particularly in the community? I've heard you talk about church before, taking Jennifer to church before.

SW We go to church, we haven't really taken the device to church. Yeah, we really haven't done that. I'm only supposing, just from our experience with her even with her being in a wheelchair and going out, people tend to be, people who don't know her, and even some people who do know her tend to be afraid. Kinda like- What should I say? What should I do?

DH That's what you were saying before

SW Not knowing how to interact. Now Jennifer just got a new electric wheelchair so people are like- oh gosh, you know

DH Here she comes.

SW Here she comes.

AH I think also anywhere you go you draw more attention because of the wheelchair and they wonder what's wrong with the child. It's just a curiosity, so you feel like anywhere you go people are staring at you.

DH With or without the device, I take it.

AH Exactly,

DH just being wheelchair bound

SW Well, I think that, I haven't figured out how to make it work exactly yet. I think that one issue is that some fear. I'm always a little bit afraid because the school district owns the equipment and it is expensive and everybody is always working under tight budgets and stuff. So I do have fears of it getting damaged or broken or you know those sorts of things, those practical things, but also how to integrate it. How to make it work.

AH exactly

SW When is it appropriate. When is it a good time. I think communication is so important you know. I don't think the wheelchair isn't even as big of a deal, I don't think, at least for us. We pretty much don't think, it's almost invisible to us other than you do have to load and unload from the van and stuff like that, but just god to be able to communicate. If I could have one thing in the world, it would for her

AH You know that's another with these devices. You have to program with Brooke's anyway, you have to program certain things in there. So maybe that's not even

DH What she would want to say.

AH to communicate about

DH that's a real good point

AH so it seems like it's really hard to find something they can actually communicate with on their own.

DH How can you read somebody's mind and think what they would what say exactly.

SW Right, what would they want to say.

DH That brings me to an issues of things like, and this isn't on here, but it's just a curiosity of my mine. Things about initiation, do the girls feel like somebody has to turn to them and then they get a change to use the device or is there some sort of built in thing where they can draw your attention to them if they would want to say something.

AH Brooke doesn't have her device with her.

DH Does she have a vocal way to call you.

AH No she doesn't. She can make noises, but she usually doesn't. She's pretty quiet. I think she's kinda shy to begin with.

DH Oh really

AH But she can definitely can get people's attention by smiling at them. She'll draw people's attention that way.

DH Just through that venue. So, she's going with the nonverbal communication.

AH Exactly

SW Jennifer does initiate. That's been, it's been exciting, but it's almost like it was a bitter sweet kind of experience because I know we'll be out and she'll- we'll be out at the mall or something and she'll say hi, you know she can say hi, how are you? Then they'll say how are you? Then she'll say fine, and then she's like stuck and then she'll say hi, how are you because she loves to interact with people. I mean this a is child who is not very shy. She's a little bit afraid of people she doesn't know, but she loves to interact with people. It's just a little bit heart breaking sometimes because she wants people to stay and talk and she'll grab them by the arm and she'll want.

AH Do you ever find that they're kinda shy about- I don't know what to talk about, I don't know who she is

SW Yeah, yeah I see that in people, once they get beyond the general pleasantries. Then they don't, but every once in a while there will be somebody to continue on, like I really love that outfit you've got on. You have the best hair. Your hair looks great today. And she's just like thanks. She can say thank you and she just loves it, but a lot of times, people get once you now hi how are you people get uncomfortable and don't know. I guess I've grown to understand more that it 's- I live with her so I think it's easier for me to continue that one ended conversation, but I think after I really had a chance to really think about it and I guess come to terms with some things, I realize how hard it must be for some people to continue a one sided conversation. That's why the child being able to have some way to communicate is so important.

AH That's how Brooke is, she can't even say hi or you know.

DH Sshe starts with her smile and gets the attention.

AH They'll say hi, how are you? You have a pretty smile. It's kinda dropped. What more do you say? I a lot of times find myself answering for her,

DH I was just going to ask you

AH Say good bye, we'll see yeah later.

SW Just wait now, Jennifer is getting into moving into puberty and she gets mad at me. If I slip and do that she gets mad. She'll tell me- leave. She knows that she has difficulty maintaining that interaction, but she does not want me helping her. She does not want me helping her. She doesn't care. She wants to go out on her own. Actually I've come to realize that it's better for me to leave because then I don't, then I'm just like keep my mouth shut. I'm not interrupting her. I'm not making decisions for her, so it's best. It's practical. It's safe for all of use.

DH That could be really hard

SW Oh, it is, I'm going through some real adjustments

DH Puberty, uh, thank goodness we're a long way off from that at my house. She's only five of course she acts like a teenager sometimes. Okay, we've talked about a lot of these things. There's a question on here, we've been talking about community, but as far as interacting, as far as going to restaurants. I know that there's a wonderful park in Highland and you have a big festival once a year. Access to community types of things- it just says does the AAC device affect you ability to take the child to the community to those sorts of things.

AH Brookes' devices wouldn't. We can attach it to her chair.

DH It just rolls with you?

Both agreed

SW We have a mounting device. We haven't taken it to those kinds of places, at least not that much yet, but we do have the ability to do that. We do have a mounting device, so we can mount it. It wouldn't hinder her from still moving around.

AH The big picnics and things, it wouldn't be a problem as much as in church, you know.

DH Where she want to sing something. No wonder you haven't taken it to church.

SW When the priest is talking. Jennifer would be excuse me priest, I have something to add here.

DH I see that there's a strategy behind that. Okay, attitudes or beliefs about augmentative. Let's talk about this one, this one is pretty good too. It talks about what your goals and expectations were before there was any augmentative device like when people starting talking to you about there are these devices out there and this is what could happen. Let's talk about your beliefs then verses the reality.

AH I had such high expectations. I thought great. There's something out there. It's just going to be perfect. She's going to hit one of these buttons and it's going to talk for her. This is going to be excellent. Once I got the device and seen how complicated it was for her to work. How you had to constantly program in there eight different things that she was going to say and talk about. My expectations just went real down. Just like that because it's not like-it's not what I expected.

DH Yeah, It's completely different from expectations to reality. Does the assistive tech fellow in Highland also the one that you were talking about does he come over by Brooke too?

AH He used to but now they've started with a different woman who specialized in special ed. because they are gonna to take half of her time and sit in the actual classroom with her and see how they can convert ways

DH to do some more things,

AH exactly

DH because that's what I was wondering about- eye gaze and some of those other things

AH He didn't feel comfortable with doing that he said.

SW Is she still from Easter Seals?

AH Chris, yeah

SW Oh, okay, she does have that background.

AH Yeah he felt more comfortable if she did it.

DH Good, then she can look for other venues.

AH So half of the time she's in the classroom and other half of the time she's working on Brooke's computer

DH That's great. Okay so she's getting a lot of individualized assistance. How about your expectations?

SW I think I had similar feelings as Angie. You just hope, or you have this vision

AH You see stories on TV.

SW Right, you have this vision, that it's gonna this great magic thing. Not that it hasn't been great. It has opened up opportunities and it is certainly it good, but there is that adjustment time from when you thought oh god this is it this is gonna be, this is gonna get us over a big hill here and then things are going to be so much better.

AH She's going to be able to communicate.

SW It's just so much more complicated. Just all of the coordination of trying to figure out what to use. The devices generally, or what I've found is that they don't always do the things that you invision that they do. It can be complicated and then there still is and I guess I still part of my mind still has this dreamer this expectation that technology is going to get to the point where there's going to be this thing where it's gonna be the right thing for Jennifer.

AH And you talk about it with her teacher and everybody. Everybody keeps saying some day there is going to be something.

SW Someday there is going to be something that will get her thoughts out of her head.

AH Either it's the device or it's us trying to figuring out how she can communicate.

SW So I think that I still hold that a little bit even though I've, we've dealt with reality with the devices that we've had on hand.

AH There's something that's going to come along that's better and easier.

SW right, right

DH That brings an issue of funding. When we talk about things that are out there. The school district I guess has bought Jennifers'. Have they, is it their IntroTalker too?

AH No it's Brookes' IntroTalker.

DH It's actually yours. How were the funding issues for you then as far as finding.

AH It was a little bit of a struggle finding who to go out there. Who's going to help you pay for this. How to go about it. Then once you do find some place to apply. You have all of the paperwork. You have the waiting period. Ten you have all of the questions about is this actually going to help her. Well, your not sure. Your never sure.

DH You talked about training when your got yours. Did you get training too?

AH It was just a basic training saying this: is what you do, this is what it does. If you have any problems there is an 800 number on here.

DH So feel free to call.

AH Exactly

DH Your is a Prentke Romich device?

AH Yes

DH Who does KN:NX? I can't remember, Don Johnson?

SW Don Johnson is where it came from. We didn't actually have anybody from Don Johnson but we kinda Rochelle knew she was already familiar. Easter Seals already had that equipment, so the people that came it was Rochelle or the people afterwards they were familiar with that equipment. They basically did the training. We didn't, it was not. I think that Prentke Romich, I think that's something that they offer with that device.

DH Sometimes, it just depends on who's available.

SW Really, I wasn't sure. We were, actually it was probably that we were lucky enough to have the connection with somebody who already was familiar with that equipment. Don Johnson has been really good. I think that if we would have had some issues they would have helped us out.

I don't have any reason to believe that they would not be willing to offer some training or help. They seemed very open to that but we did have access to some already.

DH Someone in the community. Did your training come through school, Angie? Through Brookes' school or just through Prentke?

AH Yes, exactly

DH Did somebody come to you individually?

AH Yes, She came and said I think this would work the best for her.

DH Had she seen Brooke or spent some time with her?

AH She came and visited with Brooke and I.

DH Was that Teri Madak, the lady from Prentke? Okay, great.

AH Yeah, I couldn't think of her name

DH She's got about three or four different states. Generally, if somebody in Missouri gets a Prentke or somebody or here gets one it's usually Teri Madak that comes out to visit.

SW I don't know if this applies right here, but just saying her name made me remember. I had her come once when Jennifer was probably about six and she came and Jennifer wasn't in her community school at that point. She was in Belleville in a segregated setting. She came and spent one afternoon with her and she said that Jennifer would be best suited to not use her hands, but to use a head wand and to use like probably the Light Talker and have it activated with the head wand. Which sounded really great. I had high expectations but Jennifer, we did put a little flashlight on a headband to just kinda get the feel. She hated it.

AH Brooke would hate it

SW She hated it. She wanted to use her hands and I could not convince Terry. Terry was like, not to get down on her or anything but this is part of another issue of professionals that she just felt like giving her disability given her athetoid movement of her arms and hands. It is going to better, she has the best control of her head, but I kept saying she doesn't want to do that. That's not what she wants and if she doesn't want to do it, it doesn't matter. You can buy her this fancy equipment and it's going to sit there because she would rip that headband off her head and pitch it. She wants to use her hands.

AH I can't blame her

SW Oh, I know

AH I would want to

DH Especially as you think of her now in junior high. As the girls as aging to have to wear a device with a light pointer would be probably fairly socially detrimental.

SW And I know, and this is something that I talk about with her. She will have to like all of us, but probably a little bit more in her situation have to come to terms with some things that she will have to do differently than other people. That will happen over the course of time I think. We try to talk about that and help her with that, but you know, I think as well as professionals listening to us where it's appropriate and where it's practical and we can do that. I think we need to talk to the kids and even if they can't discuss it with us. You can see if a child is not happy.

AH exactly

SW Brooke, she would figure out a way to let you know that this is not what I want. I don't feel comfortable with this.

AH That's where I think it's so important that the parent steps in. They know the child so much better. It's frustrating especially when the professional doesn't agree with your point of view and doesn't understand where your coming from.

DH Well that kinda leads us, let's talk about- this is my favorite question- if you could tell professionals how to work better with families when trying to identify augmentative devices, what would you say? I hear a big L word, listen listen to the families.

AH Yeah, most of the time I really can't complain, most of the time they are very good listeners.

SW Well, I think too what I seen happen people, they really want to help. They get really enthused about- caught up in what their expertise and are like oh this would be so exciting. I think that they get so caught up in it that they forget that I been with this child for an hour. I mean this family has been together forever.

AH Also I wonder if they've had good experience with another child. That this thing worked so good for that child. So they come in and they say, "this was the perfect system for this other kid I worked with and it worked excellent. I think we should try it." You say I don't think it will work for her. I think we should try it because this worked perfect for this other kid. I think it would really work good. You don't know what to say, your just

DH And that other kid is not yours.

SW Well, and look at each child and family as unique.

AH Even though two children may have a lot of the same symptoms, they are totally different children.

SW People, they're different people

DH Plus they come from different family backgrounds. That's one thing- I know that Sue has an extended family, that was one thing. I want to come back to what you would tell professionals, but as we were talking about community and extended family member How are extended family members with your girls and their devices. I don't know much about your family Angie, I just know that Sue has a bunch of sisters and brothers.

AH I'm a single parent. I have a large family. I'm from 11 children in the family.

DH They're all in the area? So how did they manage.

AH It's pretty much up to me. Everything is. I sometimes wonder if they're not comfortable or just don't understand how in-depth everything is

DH How about little cousins and

AH Are you talking as far as the devices?

DH As far as either communicating with Brooke somehow or

AH There are definitely some little cousins that communicate a lot better with her than other ones. I don't know if it's the shyness, but there's one little cousin and she's excellent with Brooke. She's so in tuned into including Brooke and she'll talk to Brooke like a normal third grader because she's a third grader also.

DH And to that one sided kind of thing like Sue was talking about

AH Exactly, they even made their first communion together. She pushed up the aisle

SW Is that Beradet's little girls

AH yes

SW Breann, she so wonderful

AH She wasn't a bit worried about you know what her classmates would think of her, nothing bothered her.

DH She just did that with Brooke. Oh, that's wonderful.

AH She's one of the better ones.

DH Do you feel like your family is supportive then in terms of just beings there? Maybe selected members, with great big families like you all have not everybody can be supportive I take it.

AH They're supportive in a ways as listening and being there for you, but physically being there for you, everybody caught up in their own life.

DH Exactly so it falls. Same kind of thing?

SW I think so. I think even my mom will come over and it's getting to the point where it does work very well anymore because Jennifer is getting taller and mom is getting older.

DH And getting shorter

SW And getting shorter, but my mom even has even always afraid. Nobody will have Jennifer over night. I don't know what they're afraid of but they are afraid.

AH I think it's a lot of work.

SW Yeah, it is a lot of work.

AH Everybody is so busy.

SW Right and I think there are some fears. I mean I guess I didn't really realize it, now I don't know it this happens, none of my family has admitted this, but I had the mother of a baby-sitter I had once when Jennifer was real little call me and say could she die like while my daughter is baby-sitting for her. Well, I guess any of us could die at any time, but you know she's not in anymore danger of dying than you are or me or anybody else. So I think- I wonder if I even know the extent of the fears that people have that they don't even feel they can express to me. That they feel it might hurt my feelings, but none of my family- we haven't been able to go do an over night. They're just very uncomfortable.

AH And for them to offer to watch her for a couple of hours and go on an outing. No, never.

DH Not even that little bit, oh goodness

SW I do, I can bring, like I brought Jennifer to my one of my brothers. His wife feels real comfortable and I've brought her to Dave and Connie's when she was littler. It's getting more difficult for me now that she's getting older. When the kids are tiny, I mean this is my perspective when Jennifer was tiny, it was like oh she's this tiny little girl and helpless. She's so cute and you know and cuddly and everything like that and people seemed they were still afraid , but they seemed a little bit more comfortable with it then. Now she's 12 and she's about the size of a regular 12 year old size.

DH In terms of height and length?

SW In terms of height, a little bit on the short side, but still close to the size of a 12 year old and I think now it's her and it's her height and her size that people are afraid that my family is afraid oh gosh.

DH How do we manage?

SW Right, how are we going to manage?

AH But you know they can look at you and say-

SW How does she manage?

AH So if she can do it, then I can do it. So I don't really think it's on size.

SW that's not a good

AH She on a small scale. She's only like thirty pounds.

DH I remember her being real tiny when she was little

AH Yeah she's really small, but it's just the fact that either they're afraid and don't admit that to you or they're all just so busy.

SW Everybody is wrapped up in their own kids and their own lives

DH How about reaction from extended family when you all got a device or when you started talking about getting a device was that just kinda thinking from a community-culture point of view. Did you get like people who were like don't get so excited or they were as excited as you.

SW You know what happened with us was like you know, this was really weird, well I don't know if I should say it's really weird. It seemed weird to me, because I've always had faith in what I thought Jennifer knew and understood, but once she got a device it was like people in my family, some of them and even people in the community have treated her in a more respectful, not that they were disrespectful, but they treated her- it's almost like they're saying wow she's smart. That really affected how people treated her. Thinking that she might really be thinking in there.

AH When I told them that Brooke was using a computer in school they were all shocked. Your kidding what does she do? How can she do it? It was just like she doing it. They don't realize that she's an actual person with feelings and thinking and wants to communicate but just can't physically.

DH That might be where part of that fear comes in that we talked about too, just what if they need something and can't tell me sort of thing too.

SW That just really, that has really been one thing that has struck me. The difference in people and thinking that- wow, she 's smart. I had people in the community say, she's going to school? I'm like this is the nineties.

AH Then they'll say where does she go to school at? Here in town. Here in town? Yeah, right here, right here in town. What does she do in school?

SW I didn't even tell you this yet- This lady in town said to me, they let her go to school. Excuse me, they let her?

DH It 's the law lady, she's going to school. Isn't that funny.

AH I get a lot of- What does she do in school?

DH She does computer, interacts with peers, socializing

SW It's frustrating because people, I guess I understand it on one hand. People are so, we're so used to the way we are that it's hard for us I think to see how somebody who's different would do things. For people who don't know somebody who has a disability or don't know a child or an adult who has a disability I think it's just really hard for them to imagine well if they can't walk and talk and do things like I do then what can they do. It's really difficult for people. I try and remind myself of that when I feel myself getting frustrated or a little bit angry at people, ignorant questions.

AH Because to you and I it's everyday living. It's no big deal

SW right

AH She's a little girl

DH That's- even from an age kinda thing, I was talking to my dad one day and talking about people with motoric disabilities. He had no idea that the cognition could be there and that's just from the old world thinking. And of course, I had to educate him about that, which he wasn't real thrilled about. Here's one that we really haven't talked about- what things about augmentative devices that were important to you were not considered by professionals? We could actually put you know listening to the children's- like not wanting to wear a head pointer- that kinda of things that the child might consider.

SW They're desires and their interests.

AH Also, they're wanting to fit in and not be so noticeable with this thing.

SW right

DH head pointer, etc.

SE Exactly, that's been a big issue with Jennifer. I think a lot of reason for her rejection because just like any other kid. Sometimes, I think we forget to apply regular kid things to our kids. I mean people forget to do that. It's like think about a regular kid they all at certain ages want to be just like their friends. They want to wear the same kind of clothes. The same kind of tennis shoes. They want to talk the same, act the same. Our kids are no different. They want to fit in and be a part of the gang. Whereas myself, as an adult I'm like hey, dare to be different. Stand out in a crowd, be a little different. Kids, your at certain ages and it's not cool to be standing out from the crowd, you want to be a part of the

AH I think them more so because they already stand out

SW They already have

AH in their wheelchair

SW yeah, right

AH They even struggle to fit it and be more alike more so.

DH So that might fit in with one of the other things you'd tell professionals. Is to think about the child as child- age appropriateness.

SW right, exactly, age appropriate I think is real important.

DH That's a big one

SW right

AH exactly

DH I can't believe that I said that this is supposed to be coming from you guys and it just popped out.

SW No, but that's real important.

DH It's exactly what your saying though, especially as they're moving into teen agers, etc.

AH To remember that they're not babies just because they can't talk.

SW right

DH That's a really good point.

SW right

AH You get people talking in her face right here and saying real loud hi Brooke, how are you?

SW I know, her hearing is her one perfect sense. Her vision is not great. Her speech is not great. Her touch is even not that great. She can't walk but she can hear wonderful, you don't have to shout.

AH and right in her face you know

SW Can you imagine what they must think sometimes. Wow, these people are so weird.

DH That might me something you can program in. My hearing is fine. I don't need

AH Please take two steps back

SW Your invading-

AH exactly

SW invasion of personal space

AH I really think that's

SW Jennifer has it

AH She looks down a lot. You know people think that she doesn't understand because I'm talking to her and she's looking down. She's

DH She's disconnecting and

AH exactly and she's like get back a little bit

SW Try to imagine, if we talked and I was like two or three inches from your face and people were like constantly in your personal space.

AH And looking down on you

SW yeah, exactly

DH That's a cultural thing too, because some cultures do speak more closely than others

SW But here in American, we really I think we our messages in society are about having personal space. I'm sure, I know that our kids see their peers having personal space and I think that's something that we're not conscious of those messages.

AH Well it is if you pay attention to little infants. Grownups come down right in their face. So that's what I associate somebody in a wheelchair that can't talk. You know a little infant laying in there.

DH You know that one thing that infants do to, if they've had to much stimuli. They do turn away.

SW right

DH It's just like oh, I have to resolve some sensory issues. That's probably something that she's done for a real long time and it's still working. I always laugh about that about talking down on little children that's what they draw faces with nostrils that look like you know big circles.

SW Because that's what they see

DH That's what they see. You know, you'll have to ask Jen and Brooke about that one too. Um Okay, we've got a couple of things about professionals how to work better with families. What about funding? Should they be more up front right off the bat about funding issues or that's always a touchy issue?

AH I don't see why not

DH I don't see why not either

AH What's there to be afraid of I mean?

SW right

AH We need funding to help us pay for this device

DH And talk about various venues um

AH exactly

SW Well I think part of the fear if your looking at it from a school district perspective because perspective according to the law if your child needs some sort of a device not even necessarily communication. I mean if you know, whatever the child needs to be able to be in the school and participate they're responsible for and so school districts are really, I think they don't even want to enter into the conversation at all because their, where parents are not aware of that because they don't want them to become aware of it. So they kinda really try to skirt the whole thing and not even try to even look at where there are alternative forms. In the St. Louis area we you know variety club has helped a lot of people.

DH with purchasing. I just wonder if that might help with some of the stressors because it sounds like you worry about your device because yours is at school and you can't use it at home and yours is owned by school

SW right, so your worried about it

DH so it's just a continual kind of thing. If something would happen to that machine would the school be responsible for repairing? How about you Angie, since you own it?

AH The school wouldn't be responsible.

DH That would fall to you too, that would be an additional financial stressor just depending upon who has bought that. If she moves to a different device with your assistive technology person coming in would school... probably when Brooke got her device five years ago it wasn't the law because assistive tech was added later on, but that might be a venue to pursue is if she got something new that the school would purchase that.

AH Yeah, that's been a concern of mine, you know would I try to, there again your kinda in a bind because if the school owns it, it's theirs . Your kinda afraid to take in out in public in case it gets, you know so part of you wants to own it yourself but on the other hand you know, what would be easier? What would be less stressful?

DH What is cost effective in terms of getting something

SW right

AH right

SW Financially, if you put, have to try to figure out how to put together the money or

AH exactly

SW I mean these devices are expensive I mean you can

AH You can go through, it's not easy to go through these like the variety club and ask them for this and

DH or go to your community

AH or ask for donations, yeah right go through the community and give them a speech and tell them why you need it. That's all very stressful.

SW I think people really don't' know how um awful it is to ask people for help.

AH Then there again you feel like your begging, begging for money

SW It's so humiliating, yeah exactly.

AH Right

DH That might be something else to share with professionals. Come in with some solid funding ideas other than saying to you all let's go to the community.

SW Well, even approaching funding in a more of a team like way. I feel like when all of the responsibility goes on the parent.

AH Here this is what you do

SW You have to figure out how we're going to make this thing happen. When Jennifer got her first- The very first thing she was on was a an Apple II e with a unicorn board an um the this was gosh six years ago.

DH That couldn't have been portable.

SW No, it wasn't, that was not portable

DH That was at school?

SW Yes, that was at school.

AH Brooke is using that right now.

SW Is she?

AH They told me they don't even make them no more.

DH Yeah, I think we've got a few around the clinic.

AH So why are we even- if they don't make theses no more, why confuse her?

DH I think that if she's using an adaptive board, you might be, like if they get a Macintosh later you might be able to use the adaptive board, but we've got some of those around here, too.

SW But the funding thing was and um there was nothing in place in terms of the law. They were under no obligation. We, they paid for an assessment when she was like five and made this decision. Well, now we don't have any money and so the special ed. directors well we'll raise money in your community. He wrote letters and he went and spoke to a few people, but ultimately it was up to us to follow through um to call people and it was really a humiliating

AH It is

SW These are people that we live in the same community with and no matter who you are there are going to be people who are going to say they're driving a nice car why can't they pay for that. She sure wears nice clothes why don't

AH the normal judgment

SW Oh yeah, people are judging. You know why can't you, why can't they doing that themselves.

AH Then I also feel like too, they think why does she really need this. Are you just wanting this because you think it would be nice. We don't even know it would work. This could just be an experimental thing. Are you actually really needing this?

DH That a good point from their point of view and they don't know

AH A lot of it is experimental and you know what do we say we're not 100% sure she can use this but we gotta start somewhere. That's why we need the funding. We sure can't fork out all this money continuously for these devices.

DH Especially as devices keep, well some are getting cheaper and then they come up with something out of sight that might be the one

AH exactly

DH and it's so expensive

SW I think a lot of folks and at least this was our experiences in our community when we did this. A lot of the people in these like: the JC's and the Knight of Columbus and those types of people. Those are old guys. I mean

AH Old people that aren't in tune the

SW They are really kinda working on standards, values, and ideas that are really from a different time period where people with disabilities weren't you know like you. They go and live somewhere and you don't see them. You don't hear from them. They're not in the community

AH in the school system

SW So they're really working from a different framework. I had one guy say you know I hope she likes that new toy when we got the Apple II. I'm like well, um that's not really what it's about but I tried to be real nice about it because they did give us money, but they were really working from a different framework of thought. They did end up changing their mind because more people starting seeing Jennifer in the community and heard from school how well things were going so there was so they did kinda change their mind but initially it was

AH Well, I've even had a person say that they didn't think that the community should be spending money on making the sidewalks into the ramps and things like that.

DH accessible, oh boy

AH They thought that was a waste of money.

DH It's interesting too when you go into a community that not like, it's not a particularly wealthy community so people are kinda striving for their own too. Then to have to ask for things above and beyond that's hard. That's real hard.

AH exactly

DH Good point, okay um how about the role of professionals when trying to get to work with you to get your child an AAC device. You know you talk about different roles-you talk about consult, and Angie has talked a little bit about expert consultant here are the things and then Angie has talked about the part this worked for one child, this should work for your child. What about the role: front seat, back seat, where should they be?

AH Gosh I don't know, that's a tough one because you want to be at the same level actually.

SW right

AH You don't want them to think that they are higher and above you. You don't want to feel above them. You need to be on the same level.

DH That's a good point.

SW It's good to I think just in all of the things we've done. If you can have this role of team like effort where there are some times when you know I got things under control you know whenever I can I like to be I like to take a leadership role. I don't mind doing leg work, but there are times when you know

AH you really don't have

SW Jennifer, we're getting ready to have a surgery or we're getting ready to a big doctor appointment and I have got to focus on that and it's like okay can somebody else on the team take a lead role now. So if you can do that from that perspective or that framework of having a team effort and people being

AH Sometimes to I feel like we do try to be so much in control because we feel like they're in our life. We have to care for them and so sometimes I feel like too we need to back up and say go ahead and be in control if you've got ideas you know let's try it.

DH So really a collaborative kind of thing were people listen to one another and

SW I think that what you just said is real important as something that's...... I really struggle with..... I really tend to be somebody that's like

DH do this

SW You know I do, I know that I tend to be that way. I think one of the most healthy things that has happened to me over the last couple of years since Jennifer has been in the community is learning how to have an increase trust level and back off a little bit.

DH Kinda delineating a little

SW Right and just say okay. Giving them the message like I trust you guys. I'm here you know I trust you guys to a certain degree and you know I'm gonna back off and

AH it's makes me also think of the family issue. I honestly think that a lot of times they don't do a whole lot because they look at you from the outside and think that everything is in control. Your doing so well, look at them, what can we do? you know

DH Exactly, from the little tiny part that they see

AH Exactly, they look at you and it looks like your handling everything so well.

DH So maybe from a team point of view, did anybody have a social worker that they worked with that talked about funding. You know how you have a hospital based team just mostly assistive tech, speech path, special ed. for the most part team wise. Okay, all right. I've pretty much worked through all of the pointed questions. Not so much that I had to pose them all to you but they kinda came out in conversation. It think we've talked about attitudes and beliefs and goals and expectations um let me see if there's anything. We've talked about community. We've talked about extended family. Here's one do you think that the values and beliefs of professionals are different from yours and if so how to these differences affect what happened when decisions where made about augmentative device? I think that maybe we've touched on that a little bit the professionals that come in that everybody wants the best, maybe

AH Yeah, yeah, the professionals that we're working with is mainly in the school level and like she said earlier. They're more in tune to the academic. you know

DH So from a point of view we yeah we have talked a lot about that rather than working on the devices for true social pragmatic communication it's more academic based.

SW Well, I still think that um just every once in a while somebody a let slip a little comment and it will make me think that they're still people in the back of their mind even though we're working with wonderful people. That people still have a hard time thinking what she ever going to do anyway. Every once in a while somebody will just come out- not

AH Are we wasting our time?

SW right

AH Even though they don't say it, you kinda wonder if their thinking it.

SW Right, you get that feeling sometimes that they think well you know well this a mom who just can't accept reality here. She's in denial and what is this child and what not to a large fear and it doesn't make me mad really because think it's part

AH it's frustrating

SW It's frustrating, but it's part of their- I mean they were raised that way. A lot of these people are our age, older you know in the forties, fifties you know really grew up with different ideas about what people with disabilities can do.

DH And trained in a different era too.

SW So I think we spend a lot of time educating people about how things can be

AH That time could be geared toward something else.

SW You feel like your constantly- and most of the time- that's it's okay,

AH Right, it's not an issue

SW But sometimes you do. You just get tired you just think

AH Even the time and the effort you feel like it's not all there because they feel like what can I do. Is really gonna get anywhere?

DH Then they're putting more demands asking you to do this do not etc., etc, in differently therapy venues.

SW Well, it's always gonna cause this is what I've said to people before it's like Jennifer's part of your life for a year, maybe two years. She's always part of my life. She's part of my family. You go home at night and I'm not devaluing anything that you do or you know your job I mean I respect that and your a credential person to me but you go home at night, you go on vacation, you could switch jobs, you could

DH move

SW right, but this is my life. I'm looking at more than one year here. I've got twelve years of history and I've got a lifetime ahead of me.

AH This is their life we have to find something for them. It's up to us so that they can live a better life.

SW Right, I think maybe sometimes it's hard especially school people because a lot of times you switch. You know every year so I think maybe it's hard for them. They're focusing on what they need to get done in this year.

AH And it takes them how long for them to even get to know the person, the individual.

DH It's hard with a five or six hour day.

AH By that time they're moving on to another teacher.

DH or it's summertime you know your in the fall and things are going well and you finally get to know someone in the winter and then schools over.

SW I think we have to look at it from a real long term. What will, I mean you don't concentrate on it everyday but every once in a while be like what about when she's sixteen? What about when she's eighteen?

AH But that's our goal.

SW Right, where do we need to be? Where do we need to be working toward? so that

DH Your talking about transition basically because they will be in school until they're 21 and then what happens? Funding changes at that point so those are some that could be a concern of families just in terms of what goes on after that we could share too.

SW I think maybe it not even be in our conscious thinking but I'm sure that it's in my unconscious thinking. Like okay, we're using this device, how does that translate into the future in terms of goals for friends and for academics. It's more than just a looking a one year block of time for me.

DH Even the work world they talk about real life training. Suppose Jennifer takes a job somewhere and how is that going to kinda condition to where she is going to be or transition. There's that big word again.

SW She told, she's telling my husband that work in the office with him. She's going to be his assistant.

DH What's he saying? okay

SW Well, right now he's saying okay

DH Until he realizes that he has to drive the van over to west county everyday instead of his car. Okay, let me just kinda bring this to a close. Thank you so much you all have shared some wonderful information and as you know that will be compacted into some kind of training for professionals so that we get a family point of view. Sue hit on one point as we've been going to a lot of family sorts of things. That is the family is the constant for the child. That the team members change. The school personnel change, but you all are the constants and that's a real good summing up point anything else that we haven't covered that you all would like to say.

Focus Group with Vendors

June 19, 1996

Mary Blake Huer, Ph.D., C.C.C., Moderator
California State University-Fullerton

Summary Background Information

Type of Group: Vendor Focus Group; conducted by Dr. Mary Blake Huer, California State University-Fullerton

Date Conducted: 4/1/96

Where Conducted: Classroom on California-State University-Fullerton campus.

Number of Persons Present and Roles: 2 vendors: Phil Lawrence, Director of Marketing for Words Plus who has been involved with augmentative communication for a little for three years. Most of that time was spent working in the field with users. He has seen over 300 individual potential AAC users and has worked across a wide range of individuals from very young at three years old on up to people in their 70's and 80's, across all disabilities. Steve Bennett, employed with Sentient Systems as a sales representative, who works in the field of southern California with AAC users ranging from children from two to three years old all the way up to older individuals with strokes.

Logistical Issues: Low attendance. Pat Perault of Prentke Romich company cancelled on the day of the meeting due to a medical emergency (back problems). All questionnaires were completed as scheduled. No special circumstances were noted.

Modifications Required in Protocol: None

PL: I'm Phil Lawrence. I'm director of marketing for Words Plus. I been involved with augmentative communication for a little for three years now. Most of that time was spent working in the field with users. I seen over 300 individual potential AAC users. Worked across a wide range of individuals from very young at three years old on up to people in their 70's and 80's, across all disabilities.

Synthesis Statements

1. Family "shoulds"
   - Be able to see range of device
   - See which device their children can access

- Long term needs of user should be considered
- Family would work with slp's who are trained in AAC

2. Problems Encountered with Families
   - Problems occur when there in mismatch between expectations of family/user and device capabilities
   - Ineffective devices may be selected
   - Needs change over time- wrong device selected
   - Devices are very expensive
   - Families don't understand devices
   - Families need more training
   - Failure to consider demands placed on family and environment
   - Families want immediate results
   - Differences in perceptions between family and professional

3. Positive Effects of Device
   - Elevates stature of user in family and community
   - Can communicate more quickly
   - Increases capabilities, growth, personality
   - Reduction of stress in individual and family
   - May facilitate bonding between parent and child
   - Gives user a "voice" - can engage in family, discussions
   - Stress for user and family reduced
   - User can interact with others in family/community
   - More social interactions in community
   - Enhanced self-esteem

4. Issues for Families
   - Stress and limited time for device
   - Maintenance issues
   - Ease of use high priority
   - Accents viewed as important
   - Mistrust of vendors by native american families
   - Funding- # high priority

5. Families and AAC Decision Making
   - Families are pivotal in the decision making process.
   - Families should be involved in all phases of evaluation process
   - Education of family during evaluation process critical
   - Families should choose from available devices verses waiting for new technology.
   - Trusting relationships among all team members important.

- Positive or negative experiences result of amount and accuracy of information provided.
- Families are becoming more sophisticated
- Families demanding greater vendor service

Transcript

SB I'm Steve Bennett. I'm with Sentient Systems. I'm a sales representative. I work in the field of Southern California with AAC users ranging from children from two to three years old all the way up to older individuals with strokes.

MH The purpose of the grant is to look at AAC devices and they want to look at how families and professionals make decisions about securing those devices. So they're collecting information in order to provide materials so that people can more informed choices in the future. That's the whole thrust of this. When they talk about AAC they're really focusing on devices. They're not any other aspects. The first question and each of you can answer it. What do you perceive the goals or expectations would be for families who want devices but haven't received them yet? So what do you think families want from the manufacturers before they ever get devices? What are their expectations? We're looking at before and after.

PL Before, certainly they need to be able from to have the ability to contact companies such as mine and Stephens' and have a good thorough product demonstration. Hopefully, with some support team people being there as well. Being able to get a good feel for what it is the particular devices can do for them. So they ought to be able to have the opportunity to see a wide range of communication devices. Certainly, as one goal.

SB I would add along with being able to look at the devices, being able to see devices that their child or that their spouse is able to access, able to understand and use effectively and easy to understand and use. Be able to meet their goals as far as communication, the output, the quality of speech output, whether it is digitized or synthesized and be able to be whether it needs to be portable or mounted. Those would definitely be goals I would think that a family would be looking at. They may or may not understand that at the time. That before they go to look at or learn that there is something out there.

MH Okay, great. Another interest is positive and negative concerns and effects . I'll start with you Stephen, so we kinda alternate since there's just two of you. Can you think of any experience where their goals or their expectations with a particular consumer changed after they received the device. Where the goals you stated weren't met or were?

SB Being positive or negative or just that they weren't met after they received it?

MH either, just kinda expectations that changed upon receipt of the device.

SB Anything that comes to mind, is usually when somebody hasn't had the opportunity to see a range of product. They end up with something that's not necessarily meeting their needs. What they thought was meeting their needs until later that there was something else and they realize that they did not receive a thorough evaluation and recommendation. That's what comes to mind.

MH How about you.

PL I would agree with that and additionally sometimes what they that can happen very quickly after receiving the device if they find the device doesn't meet their needs or often times you'll see where that particular user was going what their needs were going to be in six months, one year, one and a half, two years down the road wasn't well thought out. So the device they get here which might even be an inexpensive high end device, a year from now doesn't meet the needs because they've out grown it and now they're in a position where they are not able to go get the five to seven thousand dollars to fund what they need right now. It's important to look beyond just right at the end of one's nose in terms of what the communication needs are.

MH Any other comments on ?

SB that kinda covers it

MH I think in listening to Dr. Parette in Missouri it was interesting. I know from his perspective when you think of public schools that have limited resources, the fear and one of the purposes of this grant is to not have people expend whatever limited and then there's no more money.

PL right

MH So the thrust of this is to make good decisions. Which is why he's interviewing all the different groups. How do you think device positively impact families lives. What experiences have you had where the presence of an AAC device had a real positive impact then on the families.

PL sure, I've seen just time and again where we go to a family setting where the individual has virtually lost all ability to communicate effectively except in some slow laborious process. You see great strain and anxiety that it puts on the family to communicate with the individual. So having the device there and now enabling the person to communicate in ways that they couldn't before reduces the stress level on the family. The other thing that it does which affects not only the AAC user but also the family is that um in the case of let's say in the case of a younger users, maybe a child with cerebral palsy who is involved motorically. The family, by having the AAC device the child is able to show what their potential cognitively and so then they're are viewed a lot differently by people around them. That also rubs off on the family so it makes it a little easier on the family many times. It raises the stature of the AAC user in the eyes of the community so to speak. So just the immediate meeting the needs of the user in the family setting would also stature. Those are a couple of positive effects.

MH: Stephen

SB I would have to agree. I mean that pretty much cover it. You see it from ALS that can't do anything and use a very slow method to communicate with a specific AAC device being able to communicate more quickly with ease and because it's so specific to what they actually need instead of some sort of something that was put together for them on a computer or whatever method they might use. It definitely increases just I guess their capabilities that they can do something and you see a definite improvement in just their way of life. And with the children do just see so much growth and openness and you see so much personality because of what they can do and it that way I think it definitely improves family way of life.

MH How about negative? Have you seen any time a device this is a hard question for manufacture's where it negatively impacted the family?

SB I seen cases where not, I don't know so much negative as you see parents because we're talking about within the family don't quite understand the use of the device where they need more training, where the parents need to do a little-go to school and understand the use of the device for that child and how it's going to be used because I've seen them take it away thinking it's entertainment. Part of using it is a little bit of entertainment and some of it is communication and some of it is a training tool. The product and the software that are in most of these devices have that capability. Sometimes you see a parent, maybe take it away because the child is having fun or make the child touch a certain place when the child wants to do something else. Maybe that's a negative side to it, but I think that's more lack of education for the parent. You see that and you see that in the school because that's probably one of our biggest places that we see lack of education on the professional is with our speech therapist in the school and our special ed. teachers and our regular ed. teacher that have never been around it. If there's any negative in this field it is that there are not enough people that know enough about it.

PL I have on particular negative aspect. I can think of having an environment that creates a negative aspect might be a lot of times or sometimes we don't look at the environment that the communication devices is going to be used in and to the degree that we're trying to do this in extended care facilities is another environment where it's just very very difficult to have a sophisticated, a successful sophisticated AAC intervention in that environment because of the demands that are already put on the staff there and they just don't take responsibility for the equipment. In that case I have a client like this who has been through four rest homes in the last two years and here's a fellow that is cognitively intact. He runs a computer system has locked in syndrome, solely. The staff can't even get the computer out and plug it in and turn it on and put the switch in the guys hand so that he can use the device. So in this case, this is having a negative impact on this fellow because he knows what he could do only if people would do it. And so the message there is that we need to think about the environments that these things are going into, fix them where we can, but sometimes your better off with maybe a different kind of intervention given a certain scenario.

MH That's interesting cause one of the probe questions how do you think the presence of devices affect the organization of the environment. So you could discuss it with regard to home or facility and the example you just gave. Is there any change in the way the home is organized? Is the environment maybe we're getting beyond augmentative devices, but can you think

SB You get into mounting situations and you get into doorway situations.

MH Can you speak to that a little bit

SB It's a not I was thinking about that on the earlier question on the form cause with our new device you have environmental control capabilities. It's not a major change in what we're going to rearrange, but you definitely are programming in the remote controls and doing the lights and what not into the AAC device and it's being able to access all of that which you know as we think coming from the manufacture end is definitely a positive, but you are adapting the environment. That includes whatever the equipment is in the house. But again when we talk about mounting and especially in a nursing home situation where your mounting one wheelchair or on a bed table um or on a bed or your mounting on a wheelchair and the chair is going through the house. These are all aspects that you have to adapt and kinda of this whole scenario with AAC we're always adapting with assistive technology really, we're adapting at form to make it work within that environment.

PL I don't know, it can even expand um assuming your thinking that so far we're kinda thinking about a person with a particular device when in reality there's a lot of different modes to augmentative communication and that I can see and have seen where maybe a user has a sophisticated devices as the primary device but they have other forms of communication from letter boards to things on the wall, up on the wall if they're bed ridden ah they can provide easy access or quick communication to certain kinds of needs with certain partners so there's a there's lot of potential for ah arranging the environment to need the person's communication needs depending upon what their capabilities are.

MH How about roles and relationships with family members? Have your seen shift in roles or the types of relationships between family members when augmentative devices where then present?

PL I have, I know of one example. The answer is yes and sometimes I think cements existing roles that are already there maybe, but at the same time I know last year I was at a conference in Nebraska and had dinner with a parent who was telling me about her husband not having a real good relationship with their son. Her son had cerebral palsy until an AAC device was brought into the family and um it was almost like the father did not have a lot to do with this child and um did a lot with the other children but you know did not really do much with this child, but once the AAC device was there ah and this child could participate in some things it got to be a nice bonding between the father and this child. They got to the point the mother was telling that they were working on possibility the marriage breaking up and that kind of stuff. What that was help resolve, help turn around a bad situation um, so you see that at the say time it were it could be a negative side to that you know where maybe so much attention is being given to the person that somebody feels left out. That kind of thing, but I would say that's but I would say that's rare. It's usually the other way around more bonds being made rather that lost.

MH How about you Steven?

SB Definitely the answer is yes and the one that comes to mind, it's a situation cause it's a very good friend of the family that became very close friend in Phoenix. His son had a device, a digitized device and grew autistic tendencies with this child and there's five kids in the family and they're very tight family, but ma ma always tells the story that now her son can actually have an argument with her and he'll sit there and say he wants pizza,. He wants Pizza. She say no you can't have pizza and he'll sit there with his machine and pizza, pizza, pizza until he wins the argument. So I mean there's a positive, he this is what it is. It changed the way, it gives them their voice and that's you know and you always see in family to family to family when there are sibling how they support and work and help take care of the user whether it's with the device or with whatever.

MH Those are some great examples, how about speaking of families again, stress, time demands any of that? Is there any impact on the stress level families might experience with children that are physically challenged or on time demands that the devices may or may not place on their constraints.

SB I think, one of the things that my company has looked is to make it as easy to program and as fast to program. That's one of the concern in the field is that there is not enough time to do all of the programming, and to do all of the care and to always update what's on there and to make it easy and fast to do is important and I think the fact that my company has looked at that is because they've looked at the field and said there's definitely this situation as far as stress and time, but you know as far as time and the care for it that's definitely a situation. I mean that's, taking care of it making sure they're charged and the care of the device.

PL Particularly among the adult users, Steve was talking earlier about the ALS populations. I would say that with adult users most of the families, many times I seen the family as the one most being the biggest advocates about getting the device can the stress level is already so high with them in terms of not being able to communicate with this family member that they want something there that's going to make it easier. The other thing that's kinda interesting sometimes. I have fun with this and all the higher end devices have ways to the allow users create lengthy things and speak them real quickly and that kind of stuff. I always point that out and talk about some of the strategies that you can create. You can create some of the world's greatest honey du so you can talk about this scenario with family members and maybe there's other adults and one persons working and the person is home all day with maybe some support staff. You can just see the ?shoes? light up when you tell them you can ask questions like when is the yard gonna get mowed? The house needs painting. This needs done. That needs done. Really what's happening there is that the user is getting control again so a lot of times their stress level goes down. Then I look at the other person when we're telling them this and they're looking at you like you unleashing a monster here. They're stress level goes up. (laughing) I think over all is reduces the stress dramatically.

MH The ability for the family to re-enter or continue to be in the community um can you speak to children in the community like eating at restaurants, social, recreational activities, in terms of impact as a result of devices? Steven you want to start.

SB um

MH It doesn't matter, social opportunities, participating at restaurants something where they're in the community more

SB I think anything, I think most of the time when we're dealing with children with disabilities and you give them some of the power to go out and do and once they learn that they have power to communicate or to activate whatever there environment or whatever they are doing is that their personalities and most of them are not that shy. They want to say hello. They want to talk to you. They want to communicate to you. They want interaction. I find just over and over you usually see that they want the attention and when I see them out in the community with a device I don't think anything changes. I think you tell them to order at the restaurant and let them have the ability to tell the person, what's funny is to watch not the child communicate, but the interaction with the waitress or the counter person or whoever that is first time that they have ever encountered this type of thing and let them interact. It's the same thing when I work with individuals that come to the shows, conventions and work the conventions and you let them or tell them to go up and talk to somebody. It's an interesting interaction that goes on when they communicate with somebody that's never used the device or understood that it exists or what it does or how it works.

MH Could you expand on that. Is it positive?

SB I thin that it's very positive. I think that most people then learn from that not only it exists. That this happens and no this individual who can not communicate that we used to think that there is nothing there is know generating, communicating, and teasing and joking or whatever and becoming their own person. So in a very positive

PL We have seen quite a number of times where the devices could be incorporated in the work scenario. There's a young man in Los Vegas who um cognitively is around 8 years old, 7 or 8 years old. He's 22 ,now I think. He got a small hand held device that has like forty messages on it. They have, Pizza Hut has something they call the ?turtle? team and they make a point of trying to employ people with disabilities and the turtle team folds up the boxes for the pizza. This young man through a television drive that we did there was able to raise the money to get this device and with it he can communicate with people there at pizza hut um basic kinds of things during the times that he's there folding up the boxes. He'd know gone to another shelter, kinda a work setting and he doesn't just have stuff on there about you know I want thin and I want that. There's also half a dozen messages or so telling you about the bowling game the other night. He has about half dozen things that are real important that he wants to share with you when he's done. So and just, when you see them using them and appropriate commenting on things as Steven was pointing out. It just has a positive impact on them, their own self esteem and those around them as well.

SB Sometimes you can't keep them quiet.

PL That's right. (laughs) There's the off button.

MH Let's talk about decision making a little bit now. After you've shown them devices and right when they-are ready to decide should be get an AAC device, should we not. During that decision making time what is the role of the individual family members in that there are several questions that I want to probe a little bit about decision making so in terms of the family roles to make the decisions what's your perspective on the that?

PL I think that the family in terms of being who is the overall decision maker and when I say family I'm including the user, but I think that it's extremely important that the family have the final yeah or nee vote and not get something just kinda shoved down them so to speak. So I think that the family is pivotal in that decision process. I don't get concerned when I see an AAC intervention or get involved in it where this happens where you see a family that just isn't very involved at all and um not saying that you can't have a good intervention but I think that to the degree that the family is really involved and it's just gonna be much better cause the user are in their home. They are with their family more than anybody else. So it's certainly as much or more that anyone else and that it's just extremely important that we be pivotal in the selection process and in the overall support of the equipment once they have it. So just kinda generically I would think if they're pivotal.

MH Steve, anything to add?

SB Sure, sure I have plenty to add on this, plenty. First of all I think that it's very important that the evaluation, that there is a professionally completed evaluation and recommendation made and always think that the family should be part of this whether it's after the professional recommendation is made so that all products have looked at the capability as a solution for the AAC user and after that in having the family involved in the decisions. First of all whether they understand the product, understand what it does and how it works and whether they feel they can do it. When your talking about multicultural, especially in this town. Hispanic families and every type of different individual in different ethnic background you find some families more aggressive, some not so aggressive. The more aggressive they are they more they learn and the more they have educated themselves about the product and they more they press their opinion on what they want and what the don't want and why. As long as they have learned from the professionals what is what and why it does what it does that leads to a better solution or better decision. When you think that you have therapist who make recommendations, think one way you tend not to get a full spectrum of all of the products and then the family may or may not have any say in the situation and they don't get educated. So I think it's very important to educate the families, educate the professionals and then work together on the evaluation. It's, it's like Phil said it 's so important that the family participate. Hopefully, they not participate and understand but they continue to be part of it because that's the only way it works.

MH What are the greatest concerns that you've seen when families are making decisions and they worry and they say well.. and they're mauling over this or that. If you had to list the concerns, could you list some that frequently seem to pop up during decision making? What are the families worrying about?

PL A lot of times, I don't know, I'll just rattle off a few and see you can think of some that I don't come up with Steven, but I'm sure your will. A lot of times the family is concerned that the devices that well that not enough devices are being considered or that maybe in the scenario where maybe there's an outside funder involved whether it be state, federal or school which is a combination of state and federal. Maybe they're going for the least expensive approach rather than the most appropriate. I hear that quite a bit. um Sometimes the family is concerned that the support staff doesn't really understand themselves what the needs of the child are or how to implement some kind of an AAC solution. So it has to do with the appropriate of the device. May times the family thinks that the child may or is capable of much more than what the staff is saying that the child is capable of doing so that creates some friction. Cause the issue again, particularly where it's funded they're only going to give one purchase every so many years and not much shorter than about five so it's important and the parents ought to know this after they get involved with this. It's important that the right choice be made otherwise, if they buy something and like we were saying it turns out it to be, it doesn't meet the child's needs. The child has more capability. The other thing has to do with, many times the family wants everything to happen right now. I have a lady that I've been dealing with, a mother that has a daughter that's a teenager. She is cognitively intact. She's very involved visually and motorically and um it's a degenerative disease and she wants a device yesterday and we haven't even started the assessment process yet. There's this particular intervention is going to be difficult because everything you need to consider is amplified in the particular case. She doesn't want to go through all of that. She wants a device there next week, so let's get everybody in here and in this case you need to take a little bit more of a motorical approach. I have those kinds of issues, the timing, the timing expectation of the parent sometimes is unrealistic on both sides. Sometimes the parent willing to wait. I heard in the last, I'm sure Steven runs into this because of technology, technology is changing very rapidly and so you have parents sometimes who don't want to buy this device right now because they want to see what is going to happen in the next six months. I have worked with some parents who've been waiting for the next six months for the last three years so as a result the child has sat there and not had any kind of effective intervention. Sometimes we point out to them that it's time to quit and pull the trigger. Sometimes you have to look and see what looks the best today, knowing that you can grow with this. Pick something that the child can grow with and then move forward rather than take aim, take aim and take aim.

SB The other think that I would add too, a lot of times you mentioned that the family might think that the child knows more the groups of therapist thinks they understand, but at the same time you flip it around sometimes the therapist don't think that the child knows as much as probably they do know or are capable of doing.

PL Works both ways

SB Which is the million dollar question. Whether, what is this child gonna do in a year, six months to a year to five years, to ten years whatever. The other concern that I always have is whether or not the family or the therapist have looked at all of the devices you know and whatever the company is taking a look at everything because sometimes what happens is that a family see something and it wowed by something and hasn't seen the others and stick and go with one product and stick it in their mind and that's what they end up without looking at everything out there. then that becomes a problem down the road and that happens and it's something that talks.

MH If you gave advice to families to work better with professionals what would be your list so that families and professionals would be able to work more closely together?

SB If your talking about if I was gonna tell a family to look for a speech therapist to do therapy because that is so important in terms of training, in terms of using the product I would not go through the phone book and look for any speech therapist. I would try to find one way or there, through ASHA or whatever a therapist who has experience with AAC that's first. Then there's all of the other things of personality and you know punctually and whatever else might be in terms of hiring somebody or working with somebody. Having somebody that is trained in AAC and is knowledgeable with AAC not only can learn a device whether they know devices or not, but probably they would have some understanding, but know what to use and what to do on the device. It's very different from your basic everyday being a speech therapist doing my "r" and my "s". I think that's so important because to many times they get a device. They go for training. Then will end up as somebody who does a training on the product. I do a training with the therapist on the time that they're getting paid to do therapy and that's not right. I think that if you want to do augmentative therapy that you should spend time to learn it. Then when your doing therapy with a client then your doing therapy. I think that's important and I try to always pass that on.

PL I agree that they get a team together that has experience with AAC and um and as Steven was saying earlier stress that they look, make a knowledgeable selection. Which means trying to get information on as many products as they can and also take the time from the parents, from the family standpoint. Take the time to try and come up with what is it that they are trying to accomplish. What is the goal and have that conveyed well or defined. Maybe that happens with the therapist, but they need to be thinking about that. That's a question I'm always asking people when we're going in to do a product demonstration. What is it that your attempting to accomplish? What is the environment? What is the communication? And then that gives the team something to work with as opposed to just communicate cause there's lots of ways to communicate. Steven has hit the nail on the head, you need to work with people who have experience and there's just not many of those people out there.

SB Your pumping them out.

MH Yeah, last I'm trying. Last topic, let's shift down one more time. Let's talk about culture cause we've been talking still pretty generically as we are currently and have been practicing it. These are little bit different questions now. What happens with both of you and others, you can speak for reps generically if they go in and they find a family and they are doing a demonstration or they are talking to them and they find that the family has value and belief systems that are different from their own. How do you, what do you do in that situations? Have you had that experience?

PL Yeah

MH Can you speak to that?

PL It's challenging to say the least. I think you know again somehow or another have to, you have other choice you could throw your arms up in the air and say you now I give up . Which non of us do, but that is an option. You try to understand what it is again that they are, what are they trying to accomplish? What are the things that are important to them? I worked with um it was interesting. I did a product demonstration down in San Diego about a year ago with a fellow that was from Longs who is bilingual at least bilingual maybe more than bilingual. This fellow had really does his homework. I went in there. I was probably the forth company that had been in there. He had made up his mind that he wanted a particular kind of system and that's what he heard from us. He was asking questions and I can't remember what they were cause that would be your next questions. It was things that we don't normally don't cover and it was, well he was asking something on language. The whole area of speech synthesis with a voice synthesizer that is used primarily in the United States with all American accents was he had a little problem with that, so we did talk about some ways to do some recorded speech and some things. I had another insistence on an Indian reservation where a the fact that I think that I was, well I went out to the village and it was interesting the female Indian we seemed to connect, but this young child's' father was not real interested in talking to me. I sensed that there was a whole bunch of distrust built up I'm sure from generation, after generation, after, generation about they don't trust the white man you know. So you have a lot of interesting interactions going on and those two have always kinda stuck in the back of my mind as something that was kinda different. As it turned out the mother was the one who was going to make the decision on the AAC device, so he got an AAC device, but I think that if mother had not been there this boy was not going to get any kind of equipment and it didn't matter who in there showing the equipment the fact that it was being shown by me or someone like me was gonna keep her from having it. Interesting

MH Steve

SB Yeah when I think of morals and values and usually it's not just talking to somebody. It goes a little deeper, when we're talking about the specific device and being able to adapt the device for that user so it would fit into the environment or the community is unusually the story of Mexico and being like on a reservation that the way of life and this is just one example. The way of life with the Native Americans is that the symbol system that normally we use in the Dynavox the Dynasyns, not normally, this symbols set is not what they would use. Their world is more about the earth and the colors and about the sky and the sun and things like that. So their symbol set, their concern was more that the symbol set. There really isn't a symbol set for them so this was more of a concern of how would it fit into our environment and this is something that the team had to create and think of. Being able, you usually do have questions about language and the speech synthesizer whether your using digitized or synthesized device, the question is how are we going to adapt it for my environment. Being able to adapt and making these devices adaptable and the other question is again is language. Being able to be in many different languages and being able to be understood in many different languages is some questions that have come up.

MH Last couple of questions two scenarios for both of you- think of a time when you worked really well with a family and try to speak to why it really worked and think of a time when you really didn't work well with a family and try to describe what was different. What made that not, you as a vendor, you as a representative of a manufacturing company, why maybe that didn't work both of those for both of you.

PL Usually, the successful ones are always easy to talk about and when thinking about what might not have worked out so well. I found in the, maybe I'll address the positive one and let Steven do the other while I thinking about the negative. There are um the positive ones generally have been where there's been so pretty good homework on everyone involved, the team, the family and you come in and they've either narrowed it down to the point to where they know pretty much know what an individual can do and focus on that. You go in and there's a trusting kind of relationship between all of the team members and the family. I think all relationships are very important in fact that you can get in and connect with people when your starting is important and um and where the equipment is meeting the expectations and in many cases it is exceeding the expectations of the user and then everyone is extremely happy. Um, so were you have good matches obviously, the success rate is much higher and everyone is feeling good and I guess the other thing that I was thinking too was this feeling of trust that exists between everyone involved. If you have people that are, that have some other agenda going on then that tends to have a negative impact on the over all session, but ah go ahead and I'll thing of negative.

SB I think anything negative or positive it's usually the amount of information and how correct that information is. Usually my positive situation, whether I'm doing a training or helping in an evaluation or doing an demonstration is usually when the team, the family, the people involved, when you have a positive situation they're usually involved which feeds back on you and you feed back on them. The information that your giving them and the information that they bring to the table is all working together. So they're very much, it a group effort. Things come together. You can lead them through, if I'm doing a training and I can lead them through the process and they're feeding so much information that it worked very well. The more knowledge that they have about it, the more you can feed them and the more open they are, the better it works. Usually on the negative side, the situation would be difficult where somebody whether it's a family member or a therapist is very closed minded to a new idea because the products I sell are new ideas in the field or maybe sooner or later they're not so new any more and they might be closed minded to that idea or that they come with not enough knowledge or misunderstanding something that they read or they heard. Somebody walk in a demonstration for instances on the product I sell. The Dynavox has so many capabilities and you might have so many different ways to show somebody something that you might get, if you don't plan it well somebody might walk into a presentation when you show one thing. It's looks a little bit overwhelming for them and they walk out not realizing that this device can do this for this beginner communicator and it can do this for this user in the work place doing computer programming and that they can do this to and you can reach everybody in here and that's what the companies try to do with this product. Well, they might have seen this and not seen this and they might not realize. A lot of times people will look at that and just and you have to break down these barriers where they look and they say oh, it does this. It has pictures so it must be for a child. Well, that's frustrating because obviously you never dealt with this family member, has never seen an individual who is an global aphasic you know who not a child you know but needs to have symbols or this user they might just the misunderstanding is what creates a negative situation that every good sales rep can work out.

PL (laughs) I think you know really the sum of the substance, I think what we're both saying is when you have a mismatch between expectation on the consumers part and what the device does or doesn't do that's really when you have problems and you know 99.9% of the time this is a completely innocence thing no one tries to say something to us that someone doesn't do but for some reason, a lot of people have selective hearing and um they have an expectation like Steve was saying and then that isn't met and there's this negative surprise and they're not happy. So it all boils down again to getting as much information as you possibility can about ultimately the device that's getting selected so that there is a good manage between expectations.

SB I think that over the years and in the years that I've been too short or long. I think that they've been long years actually.

PL They make the hair thin.

SB They've made mine gray,

PL He's 33 and I'm 35

SB I really think that though over the years you see more information come out where you see less of this happen and you find, the same thing that I go to abilities expos or go to C Conference or whatever it might be. You see more intelligent questioning coming from parents which you never saw two years ago um. I 'm sure, CAMA has become very important. That's another way of spreading the information, but you seeing more and me people come in. Now what they're learning is how to fund these thing and which is now the big question which is the funding. Your really seeing the information about products and the question that come from parents are no longer what's this do? What is this? It's more like well I'm trying to do this and I want to do this and I need to do this and want, I know this can do this, but I want to see how you can you do this. I heard it can do this and what about this and it becomes more of a detailed question and I think more and more information has been out in the field that your seeing improvement.

PL This consumer has special requirements you know and to talk about the user as a consumer. So from a business stand point you know you have people who have much more intense demands to support them. The mother or the father goes out and does typically speaking goes to bat much stronger for their child with cerebral palsy then when we go out to buy a stereo for our able bodied child. So the fact that the demand is putting on them means that we have to provide a lot for customer service. That is extremely high and so I think that's another part of the challenge and they're getting more and mores sophisticated and understanding that they're demanding more. You know we still get the thing, I sure Steven does to, people are not hap, for switches that's always. Doesn't your device, can't you just look at it and have the person know what picture is being looked at so that they can make the selection they're looking for. The next step is clairvoyance and part of the equipment, so they're just pressing and pressing which they should but um that is another part of it.

MH Okay, last question. Any thing that either of you, both of you would like to add? This is for decision makers, it's for families, for culture, so from your perspective or experiences is there anything that we haven't covered that you think is real important to include that would be disseminate on your perspective?

PL Funding.

MH Funding

PL Funding is a big issue. When I first got involved in this field one of the first things I did was to go to a session on funding held here locally. At that session there were representative from 8 or 9 different agencies including things like private insurance and social security-Medicaid and etc. etc. There must have been 60 people at this meeting, mostly parents. I went so that I would be able to help the client know you know how they might get their equipment funded. After listening for an hour and a half to 9 different representatives basically say well this one says they don't have the funds come see me. Well you've got this big circular discussion. 50 people didn't know anymore about funding than when they went into the game and the message I'm giving is that there needs to be I think that the government, basically we're talking government funding. There needs to be a consolidation of that and a simplification of that whole process and the thought, I remember looking over at the person that this access center and said that do you realize that if we assume that were 9 there if we got rid of 8 of these agencies and put it all under one how much more money we could have to fund assistive technology equipment because you won't nee the staffs from all the rest and it could be simple. You wouldn't have to take six months to get turned down by 8 other places before maybe you found the right one. So this funding monitory I think needs to be a real high priority. I don't know to what degree I don't know to this particular project but to AAC in general it's just a real serious situation and it's different from state to state. California has 7 or 8 different state agencies. So it just a monitory and in many ways does not but just provide long delays for equipment that was fairly mandated and needs to be and should be implemented. So that's kinda my area of one that needs to be addressed.

MH Steven you

SB Off the top of my head, no. um maybe the other thing is just looking at technology and knowing that technology is going to change there will be changes even as we come out with a new product or Words + comes out with a new product or Prentke Romich there will be change. I guess the old saying, is I've seen parents and it goes back to something that Phil talked about earlier. I've seen parent wait and say my child might talk. Well, your child might talk, but right now he's not so why wait and do it now and that's the same thing with these devices. The devices are going to change and evolve and maybe get smaller and maybe get lighter and maybe get faster and maybe be able to think a little more like our heads thing and maybe eventually we'll be able to look at it and it speaks for us cause it's... That's all in the future. We don't know what that's going to bring or when it's going to wait and why wait. But other than that ...

Focus Group with Families with AAC Devices

April 2, 1996

Sheila Hostetler, M.A., C.C.C., Moderator
Children's Hospital, St. Louis

Summary Background Information

Type of Group: Families with devices focus group

Number of Persons Present and Roles: **Cathy Mullins**, mother of 7-year-old son with Down's Syndrome who uses a Liberator; **Beatrice Franklin**, mother of son with cerebral palsy (quadraplegia) who attends Gateway State School and uses an Intro Talker; **Mary Stebleton** , mother of 9-year-old daughter with cerebral palsy who uses a Liberator; **Sue Bianchi**, mother of both a son and a daughter with partial trisomy 8 who use Liberators and Walker Talkers; **Sandy Massey**, mother of a 20-year-old daughter who used a Macaw for four or five years whose oral speech is difficult to understand; **Rose Franklin**, mother of a 15-year-old son with cerebral palsy who uses a Liberator; **Wanda Boyd**, mother of a 7-year-old daughter with cerebral palsy who uses a Liberator

Date Conducted: 4/2/96

Where Conducted: Room 5E8, a conference room adjacent to Therapy Services

Logistical Issues: This group was difficult to schedule-everyone wanted a different time, i.e., am, pm, evening. The moderator personally knew all the mothers previously with the exception of Rose and Wanda who were referred by Barb Swanson (Special School District). The moderator sees both Sandy and Cathy's children on a weekly basis. Individuals received questionnaires ahead of time and brought them to the focus group meeting site with the exception of the videotape release form. Homemade cookies and soda were served. Some participants felt the questionnaires were difficult to understand. One mother was confused regarding the meaning of the term "Euro American."

Modifications Required in Protocol: This group represented 100% attendance. The protocol was closely adhered to. Moderator felt that if focus groups had been divided by ethnic group (Euro and African American) that more cultural issues might have emerged during discussions.

Synthesis Statements

1. Family Expectations of AAC
    - Want child to communicate more effectively

- Device will make child more normal
- To hear child say "I love you"
- Increase family responsibilities, "just another thing to do"
- Some families don't want devices; expect child to improve
- To communicate humor & emotional needs (can i have a hug)

2. Changing Expectations
   - Family may prefer sound of child's voice
   - Child doesn't want to use device in public
   - Expectation change when child exhibits ability to sequence icons
   - Child's communicative competence may peak & level off
   - Child may prefer to interact with a computer
   - Mom see potential, but has to predict every situation for communication usage
   - School not receptive to using device
   - Continuity of AAC implementation between home & school is needed
   - People in community don't listen to device; still expect family to communicate child's intent

3. Organization of the Home
   - Family must remember to plug device up nightly to insure operability
   - Device may have to be kept turned on constantly to prevent loss of memory
   - Family may have to purchase bookcase to store devices-related material
   - Family loses time when device is sent for repair; programming can be lost
   - Family must unplug device during inclement weather

4. Family Relationships
   - AAC device may affect relationships with grandparents who desire a normal child
   - School not proactive in learning to use, forcing family to assume primary responsibility
   - Device minimizes need to lay guessing games with user
   - Child may be protective of device and not want others to touch or use it
   - Siblings may not choose to assist child with homework using device

5. Demands on Family and Quality of Life
   - Child with limited motor skills requires greater family time commitment
   - Illness episodes may bring set backs in communication ability
   - Moms must choose between quality of life and time investment with programming
   - Parents who home school see not change in time commitment
   - Teachers may assume primary responsibility for programming device
   - Schoolwork programming demands on AAC device inhibit quality of life
   - Families are taught how to use devices but not how to teach their children to use
   - Vendors should develop AAC training packages targeting kids
   - AAC devices may be distraction for other children in environment

- Stress comes from 2 sources: child seen as different from AAC voice; inadequate training
- Training should be specific for tasks /needs and simple
- If more support was available in school, family might feel better about personal AAC time commitments
- SLP on IEP team not interested in AAC
- Family wants AAC to be integrated into all child's activities
- Enabling child to access device can be frustrating
- Families want training from vendors

6. AAC and Community
   - Child becomes center of attention when using device in community
   - Persons in community aren't willing to learn to use devices; loot to family to interpret child's communicative intent
   - Family is proud of device and want others to see it, but prefer that others assume responsibility for using
   - Child refuses to use in public due to undue attention
   - Child wants to whisper at times but can not using device
   - If too many questions are asked child may not want to use device in public
   - Ability to take device into community settings may be constrained by wheelchair attachments
   - Device help children communicate needs in community
   - Family must predict what child will want to say in community
   - Available memory on devices limits what can be spoken
   - Devices are often heavy to carry; child might use more often if lighter
   - Persons in community are emotionally moved when child uses AAC appropriately
   - Children will want to use devices in church
   - Self-esteem of family and child increases with device usage in community
   - Children in community express interest in and willingness to learn to use AAC

7. Working with Professionals
   - Family invests time in securing device only to have device taken away
   - Professionals should communicate ownership of devices to family
   - Family member must be fully participating team members
   - If family is not included in decision-making process they will not feel sense of ownership
   - School personnel may advocate for a particular AAC company versus what's best for the child
   - Professionals need to recognize range of options for kids
   - Vendors may communicate primary concern for monetary support for maintenance versus backing up their products
   - Family may have to pay for extended warranty out of pocket
   - Family needs to see other children using AAC device prior to purchase

- Professionals who work with families should have AAC experience
- Families sometimes have to cooperatively work with professionals to learn to use devices
- School personnel often don't have training
- School personnel have varying levels of comfort regarding use of technology
- Families must wait inordinate time to receive 1-800# call backs for technical assistance
- Vendors should provide more training in use of devices
- Families must take AAC training from vendors many times
- Vendor consultants vary markedly regarding their support to families' recommendations from vendors aren't considerate of realities of family life/demands/routines
- Families resent high cost of devices designed to help basic communication
- Vendors should bear greater responsibility for training and support
- Support materials should be more user friendly
- Support materials should be accessible for hands-on prior to purchase
- Family preferences/needs may differ from priorities of professionals
- Families want guidance in making better decisions
- Families want rebates /trade in allowance on devices kids have outgrown
- Parent support groups are needed to disseminate information
- Continuity of AAC programming is needed in school: ordering/getting/ learning to use

Transcript

KM My name is Kathy Mullen. My son Jesse is um is seven years old and he was born with Down's Syndrome, but that doesn't seem to be his big problem. He suffered what Dr. Nessle call metabolic strokes when he was two and he lost of lot of the stuff on the left side, including the speech and he's been gosh he's had his Liberator I guess about three, four years now. I think, but I'm not use so um one problem he has a lot of motor problems. It's like he know the device real well, but accessing and a lot of miss hits seem to our hardest thing we work with.

SH Okay, Bea

BF My name is Beatrice Franklin and my son's name is Jason Grace and he goes to Gateway State School. Jason with born with cerebral palsy. He was a five month preemie and Jason is a quadriplegic. He also has a severe hearing loss. By him being able to talk he doesn't know how much he can hear and he can the Intro Talker. I guess about a couple of years but we've been having a hard time and we still in the process of trying to find out ways to communicate. We have tried, we're on our third device which is now a pull string. It seems to be the most effective right now, so that's where we're at.

SH Okay, Mary

MS I'm Mary Stubbleton and my daughter is Jessica Shuttleworth. She's nine and we have a Liberator and like you she's involved in the hands and the accessing of the device problems. She's getting better, so we're working on it.

SH Okay, she use an eye, an optical head pointer right now. Okay, Sue

SB I am Sue Biancci and I have a son and a daughter- Gina and Christopher who are both using Liberators and um they they're diagnosed with partial trisomy 8. Which doesn't mean a whole lot to most people um, they don't have hardly any speech and they use a lot of gestures and they do well, we're in the process of using the Liberator more frequently and um it's coming along pretty good.

SH you might want to add that they also have Walker Talkers.

SB Oh yeah they do

SH Those are the little portable

SB And they're much easier to get around with because they're both ambulatory but the Liberators are quite heavy.

SH Okay, Sandy

SM My name is Sandy Macci. My daughter's Christine and she's 20. She had a Macaw for four or five years I guess and she doesn't have a problem with talking, you just have a problem understanding her talking. It tries to slow her down, she more where she like to play with her Macaw we're programmed it and she'll press a button and I'm supposed to guess what she's saying or she wants me- she's got one on there I want a baby sitter and then ask me a question and those are the two she presses constantly cause she doesn't want to be around me and she want to know what's going on so um so She does fairly well. It's more a game to her than really learning with it.

SH Okay, Rose

RF My name is Rose Franklin and I have a 15 year old son. His name is Darrel Hayes. He was born, I always say CP cause I can't pronounce the word to plainly. He got a Liberator and he ah he's doing real good with it. There's so much up there that needs to come out and he experiment with his device and he's come up with words that we haven't heard of before and with his Liberator they have a device with they call a detector which I was trying to get funds for that because with that device he can use the phone and they say he can control the TV and anything with remote control he an use and um be use the computer with the Liberator too and um and it's just wonderful because like I say sometimes it can get on your nerves cause he could call you and me could talk like you know, so but it's really good and he just experiment with it.

SH Okay, Wanda

WB My name is Wanda Boyd. I have a seven year old and her name is Alshley Boyd. She was diagnosed with cerebral palsy. About 11 month, when she was she wasn't diagnosed when she was born so we had to find out later on cause she had such norm normality. She has a Liberator and she doing fine. She can comprehend just like you and I she doesn't have a problem with her speech except for she talks to fast. You can't understand her so that's why we got the Liberator and ah basically her handicap is physical so she was one of the lucky ones she does really have a severe disability. She come along just fine.

SH Okay, Laura do you feel like everything's working pretty well then. Okay, well just go ahead and proceed then okay um I want to know kinda what where your goals or expectations for you child's device before it was received. So think back to before they had their device, what were kinda your goals in getting that device? Mary I'll go ahead and start with you. What were your goals for Jessica before she got the device?

M Communication, which at the time when we got it was real mouthed now it's coming along quite well. She can talk quite well by herself some of it is limited and you can't understand but communication wise maybe homework and you know math spelling, things like that.

I didn't want it when I first heard about it

SH Okay what you share a little bit about that Sue didn't either

I didn't either

I wanted him normal. I wanted him healed yesterday and I still do but because what I've seen that he can produce with it and the first time I heard him say I love you mommy I about crumbled on the floor. So, it change yeah, once you start using it really changes your expectations.

SH Okay, Sue

Well, I kinda felt the same way because I understand what they're saying even though no one else does and it was kinda and they're just so heavy and I thought I was going to throw myself in front of a Bi-State bus before the training was over. It was a little overwhelming, but um after I think too it you know I'd never seen another child using one before and once I saw that then I could see where there was a lot of possibilities but up until that time I just thought just a another thing, hurdle to get over, but it's worked out well.

SH Okay, Rose you look like you kinda agreeing

RF I really didn't want it either because I though maybe he could communicate. My oldest son taught him how to use his eyes for yes and no and the teacher she was so pushy about it and one day was at the class and um she was telling me that Darrel got so much that he want to say which he can't talk and um so um she was doing some little demonstration and she asked him how many and she puts- she has like little rocks and she says how many did I drop in there and he blinked his eye how many times then she stomped her finger and said you know how many did I put in there and he said no none you know and um I still counted that to much wanting it, but my oldest, I had an older son and he was there and I had just told him where Darrel had been to get some ice cream. I don't know what happened but he just cried and wouldn't go to bed and he just told and I kept saying what's wrong and then I thought about it did you give him the ice cream cone? No that was it then I got to thinking see if he had something that if he could say then he could have let them know and you know then he got so he's kinda comical with that. He's got little jokes and everything. One of his friends was going to give him a bath and he said I'm getting really to give you a bath and he said oh, that'll be five dollars please you know. You know so it really turned out to be better than I thought and didn't to much like it cause it had, he got the pointer but it turned out to be really great.

SH Okay, Bea what were your expectations for Jason?

BF Basically, ah was just to find ah means of communications, a way to communicate because um Jay um is my inspiration you know but he's so locked in his body that he can't do anything. He has no, I mean he has no, his eyes, his face is what talks but it's no way I mean just like she said I can understand him. I know when he's wet. I know when he's hungry. I know when he's mad at me you know. When he want to go to bed or he wants to watch TV but it's knowing um well I mean like his siblings and us at home can understand but it's no way that anybody else can understand him well. So that was my biggest concern was to try to find so type of way and we just and Jay has brain damage so we really don't know just how much he can communicate but then I know that he has feelings. He's sympathetic. He cries. He could see the expression on my face and tell when I'm not feeling right and he cries and so it's just you know it's just so hard cause he's all locked up but my biggest thing was to try and find some kind of way that he can communicate you know to talk to us.

SH Danny what were you hoping for?

D I thought it was going to make it easier. That she was going to talk and I would have to worry about figure out anymore. Now, obviously it's completely different, I would much rather listen to her rather than this machine and like them I can understand her anyway. I mean sometimes if she gets very excited and she goes on and on have to pick out words but at least I know what the context of her conversation and can figure that out. To be perfectly honest we don't use our very often. It goes to and from school everyday, but she probably, the time she uses it is when she is in speech at school and not in the classroom. She doesn't want to take it out when we go out to order something like we went and had video taped her doing a McDonald's. I wanta talk. I know what I want and she's gonna tell them what she wants.

SH Wanda what was your expectation before your daughter got hers?

WB I was kinda like them. I really didn't feel that she needed it and I was hoping that her speech would improve to the point were we didn't need but they waited for a year and did some more evaluating and all that and they figured that she probable needs something else. Once she got it, I saw how quick she picked up on it and how she was teaching me to use it and I though this little girl is something else and now she's got it to the point where every night she goes mommy can I have a hug on the Liberator. Can I have a hug? Can I have a hug? Can I have a hug? and she just keeps pushing it and keeps pushing it and I though this thing has got to go. So she's got to that point where people call on the phone and she thinks something funny and the little thing laughs. she goes ha, ha, ha, so it's really neat for us. It's working out fine. We haven't had it that long so we don't know exactly what all it's capable of.

SH Well you've just kinda moved into my next question which was have your goals or expectations about the potential of the device changed since your child has been using the device? And describe in what ways they have changed. I say we'll go ahead Wanda, your kinda saying that

WB Yeah, at first I didn't want it and I thought she didn't need it but once she got it and I saw how it really helped her and how she was really capable of using the icons and putting the icons together to come up with a word and how she memorized it. I couldn't even memorize how to put the icons together to come up with a word and she's actually teaching me how to use it. SO that really turned my whole viewpoint around about it so I'm really glad she got it.

SH Anybody else feel like things have changed?
We went through a process where it was a steady up hill doing really, really well and then we kinda peaked right now and I can't decide whether it's cause he's got IEP plus I can't decide if well two things his motor as gotten worse and it's difficult for him to do sometimes to hit and he reverts to his little gestures and things like that. He'll do whatever's easiest and he's even, he used to say a lot. He sit there and recite nursery rhymes and anything else. he would just blabber on and sing songs and do this kind of stuff and people would tell him to shut up and then and now we're kinda gone down right now and I'm not really sure why. I don't know to if the IEP plus I'm teaching him how to read um he's reading once you point to the board. Like words that have the short vowel, three letter short vowel words. To spell that all out on the Liberator is just to exasperating it's just easy for me to put them on board and he can throw his hand at the one that I ask him about or something like that. So we've went kinda like this, this, and this now we're kinda like that.

SH Okay

Like I said we don't use ours much as much as we did at the beginning. We've got a computer at home and she'd much rather sit at the computer than sit at her machine and the computer talks to her and it's got sound and ever game that she has on the computer is a learning game and we both do reading rainbow and she has to read books with the computer and repeat after it and she would much rather do that sit and the Macaw and press a button and repeat what the Macaw is saying to her.

What is a Macaw?

It's a voice, it's a Liberator, it's a type of Liberator. It's just the name of the machine. It's a small one. She carries it on her shoulder sometimes. I don't think it's quite as heavy as some of the other machines

SH And it lighter weight

and it smaller

SH Don't get envious Sue. She has two of them.

So she puts it in her book bag and throws her book bag over her shoulder. She thinks that she's all preppy. She has the book bad on one shoulder and it weighs it down so she looks like, she thinks she's in high school. She says she's going to high school and it weighs the book bag down so she thinks she has all people have books- her book bad and carries it. I mean she religiously, I mean we plug it in to re-charge it and I can't forget my machine and put it in the book bag. She might not use it that day, but it's gonna go to school everyday.

SH Rose do you feel like your expectations changed after your son got his?

RF Oh yes, because ah from the school and really I like this. It's very good and ah and it's so much that he can do and he can learn. Like how she was saying how her daughter, Darrel had to teach me and I went to a class to learn how to program it and I completely forgot it. He had to show me how to do it. So you know this really, I mean this so much that he can do with that.

SH Sara did you change your mind over time or do you still feel pretty much the same way.

I'm still debating. I mean I could see where it would have a lot of potential for him, but they don't have the ability to program it and it's kinda like I have to predict every situation of what they're gonna say and you know and you know and you can't predict

They're saying what we think they want to say because we're the ones putting it in. That's exactly right.

You know it's not that simple to just ah talk into it and it's going to repeat or anything.

Can he talk at all?

Well no, well I mean they can say a few words but not

He couldn't tell you what he wanted programmed in there?

SH Well it's kinda hard

Well not really no

I know what Christine would tell me- Jamie, Jessica, Tommy, I mean like I had every friend and she know all the baby sitter. I mean the button that says I want a baby sitter is the one that is worn out.

Plus I think that if they, the school hasn't been real receptive to it either and I think that if they would use it

That was us at the beginning, yeah

You know at the school more you know then we cold work on things at home, but it's kinda like there's no continuity with it at all.

I agree with that

I agree with that too,

As far as taking it out there just so heavy

Which school do your kids go to?
My daughter goes to Wedgewood and they are very supportive. Her teacher takes her Liberator home and actually does all of the programming for me. I don't do anything but just come home

I would move

My daughter is the only, is the first child in her district to have one of them. So it's like I'm, we're kinda getting spoiled by the teacher and everybody cause the book. There's was like 12 or 13 books that came with the Liberator and I was like- I can't ah do anything with this.

I know it's over whelming

Right, so the teacher basically took the responsibility off of me and she

Especially if you've never touched a computer in your lifetime.

right

And a Liberator

And I think sometimes what bothers me is when we do take it out. She presses, oh like at McDonalds- I want a hamburger. Well they're still looking at me- What is she saying? Do you hear that think? She is telling you what she wants. They don't care

Now with Darrel they thought him at school how to program it on, to store it and um and most like if he wants to say something about what he did that night. He do it himself now.

SH That's great

Yeah

He's really, he's got a lot up there and that's why it really good and I'm looking forward to really getting a computer cause he's really bright.

SH Bea, did you feel like things changed at all after Jason go his or was still just really difficult to access all the time.

Yeah, we're still working on it

SH Still struggling with that

Still struggling

SH All right, okay the next thing we're gonna talk a bit about is we're gonna kinda explore ways that the communication device might have affected or is affecting you family. Um and I guess the one thing that I want to ask about is do you think it has affected the organization of your home, like the way your home, some people have a special place where they plug in there device. Like have you had to do anything in organizing your home any different since you have the device. Rhonda what do

I'll go first on this one.

SH Okay

What is that name on that commercial the waking up with the donuts we gotta plug the Liberator up every night. Gotta plug the wheelchair up every night. She reminds me every night. Mama plug my Liberator up. I can not forget. If you forget it's inoperable the next day. That bugs me. It should at least be able to go two or three days without being plugged up. You know that every night. I have to remember that.

The Macaw is good for two weeks

Two weeks?!

I've gone for two weeks without plugging it in.

Every night I have to plug the Liberator up. That bothers me. That's the only thing.

SH So that's the only think that you've had to change about your house.

Yes

SH Plugging that in. Okay

I have to plug it in and when I plug it in, she has to have the same spot when it is plugged in, but hers last for a long time and you know so I guess there I'm very lucky because I don't have to recharge it. The only think is, if you turn it off everything is gone.

SH Yeah, that's true.

So never turn it off

SH It's the kind if you turn it on the off button it everything is gone

It erasers everything

Group Wow

So it's always on. It's always on
That's scary

It's always on and I just recharge it even though it's always on I may not charge it for three weeks and it still works and I can plug it in and re-charge it over night and it's good for another, actually I've only three is the longest that I've tried. I don't know if it'll last any longer.

Waking up at two in the morning gotta go ?donut?
Group laughing

Gotta make the donuts

Group continues laughing

SH Sue have you changed you house environment at all by having these like is there a special place they go or.

Well, yeah there kinda is. I mean I wound up having to actually getting a book case to put. I mean I have two of all the manuals and all the stuff that I don't even know what to do, what it's for. You know all these plugs and I mean it's like I have all this stuff, I don't even, you know there's a lot of stuff.

SH So you had to buy a book case just to put

Yeah and I mean it's filled with stuff. You know manuals and the books that come with it

and training seminar books

Training seminar books and you know plus we have the Walker Talker so we have the different plugs for them, but you know so that's

SH Okay

It's all there

SH What about you Kathy? Did you have to organize your home at all to accommodate it.

Not really, um just the wheelchair and things like that are the things that most, the Liberator just goes with that.

SH Right

So I can't really say it took any main thing. It takes up my time more that any thing and when it goes the idea of the booster/rooster is that where Liberators go back to. ??Rooser??, that seems like a millions miles away, cause when that thing breaks down you have to pack it in that crate and send it and they tell you that you might lose all of your memory and you've been up till 2 o'clock in the morning putting stuff in there. It's like, let's just forget it. Let's just forget it.

Well the other thing too, there's been a couple of times when it starting storming during the night and I'm like, I panic. Like it's gonna like you know blow it out or something as lightening strikes.

That's my mine is plugged into a surge suppressor.

So I have to get up and you know unplug things.

I haven't thought about that.

Yeah, I bought the surge suppressor type thing.

All the computer stuff is plugged into that.

Well, I've still got some extra. My computer is plugged into that so I plug the Liberator into that.

And the TV, the important stuff plugged into that.

Group laughs

SH Did you have to organize your home in any way Bea to accommodate. No, it's not a problem. How about you Rose?

No, it's just plugging it up at night you know.

SH Okay, and his is on his wheelchair too, right?

Yeah, I the only thing that I have problems with is his wheelchair and some other appliances that I have there for him, but the Liberator.

SH Okay, all right the next question has to do with like family relationships with other family members so it would be like siblings, like brothers or sisters or moms and dads. Do you think that having the device has affected the relationship with family members? Sandy I know you daughter has a brother, how does that

They just adore each other, you think they don't. I mean she'll show him. She'll show it to him, nobody is allowed to touch it unless she gives them permission, but ah they're very close. He doesn't live in out home anymore. He lives two blocks away. He's got her tonight. She just called him on the phone and he calls her. No, it hasn't affected that at all.

SH She still uses, she doesn't communicate with her device.

She sits and plops on his lap as soon as he get there, so he has to pay attention to what she saying. She won't use the device at all. She's telling him exactly what's happening. What's going on and what is he going to do tonight or tomorrow whatever so.

SH Okay

It's the same

SH Mary how about Jessica? Do you think it's affected her relationship at all with her sister or with you or there other things that she been

To grandma

SH oh, to grandma

There's a lot of negative to grandma cause she's other grandma. She's like they you know she wants her to get well over night You know and it's just

SH So grandma,

I do to, but I have to face reality.

So this is just hindering her

Yeah

from doing more

Yeah, everything that anybody does

I can say that we have a lot of family support I mean my family

She's supported but in a negative way not positive so that's the only, I mean her sister I think her sister if we could get Jessie more into it which I have a problem with because I bring her here, but the school is not in to doing anything with it. I mean if I could get formatted better. Her sister has sat down and put stickers in the books and played with it and read the books. I think she would enjoy doing it with her and play guess who with her, but just grandma.

SH Kathy,

No, it hasn't really been a problem for the family. My, I have his 14 year old brother, initially it was a novelty kinda enjoyed messing around with it, but it hasn't really presented any problems. I think

SH any advantages with the family?

Yeah, you don't have to play, he can use it well. We didn't have to play to many guessing games. I want some juice or you know I want ice cream. Ice cream used to be a big thing. It was nice not having to sit there and say you want this or this. You know we played a lot of games. Outside, out in the population which I think is a lot of my fault. I'm scared to take him out with it. I'm afraid that we're going to drop it and with how much money it cost I've just been really panicky about the whole thing.

I've dropped mine on the sidewalk out in front of this hospital right in the middle of the street and it still works. It's durable believe me.

Maybe I shouldn't worry about that so much cause I haven't taken Jesse. He hasn't used it that much in public because I'm afraid to be dragging it around, bumping it around and as a result he uses it so much, he uses it much more freely with us then he does in public. When we get in public he tends to just calm up and in fact he'll turn it off and I'll turn it on and he'll turn it on.

Do you think that in public it could be because the people are in such a rush and they make him feel like

Yeah, and they stand around and stare and he feels like he's really the focus of them and you

I agree

Yeah and cause they're like don't want to take the time

and that's like they'll listen to her, but then they look at me for an answer or to repeat what she's saying

yeah

Instead of her you know. They don't treat them like they're human beings.

Like very

They're doing the talking which is what that machine is supposed to be. Them doing the talking.

Are your kids possessive with it? Like Jesse doesn't like anybody else to touch it.

Oh right

It's hers

Maybe I'm not going to use it, but you can't use it either.
Definitely, it's hers. You don't touch it unless she says you can touch it.

SH Your probably don't care. Do they?

No, they let anybody use it.

They'd give it away if they could huh?

Oh well, I mean they are proud of it. They like people to see, but they let other people use it. I think um, they play a lot of games together with it even at home like other members of the family or friends and stuff have played games with them on it. That's kinds neat cause they're playing games, but other than that as far as communicating within the family everybody really just mostly understand them and um you know just their gestures you know how they say a word, but we did have one experience when we were at a show and we went to then movies and there was a kid. I mean he was probably in his twenties and he was in a wheelchair and he was using a Liberator and then Gina and Chris ran over to him and he you know he could he had normal intelligence. He was programming it and everything and he said they look familiar do I know them. And you know like Chris went over and said yes. You know like he knew them from like a camp that they were attended, but they were communicating with him through this kids Liberator cause we don't take ours cause they're too heavy cause they are so heavy. You know do you hold onto the Liberator or the kid.

His teacher they always encourage us to take the Liberator wherever he goes and um and I used to take it. We'd go to church and I'd take it to church and everybody's so amazed over it and you know and everybody standing around and he's just talking. I guess it kinds got on his nerves because I asked him you gonna take it. No he don't wanta take it cause it bugs him to much, but now if he goes to the clinic I usually let him have it and he asks the doctors questions if he want to. So you know and I be trying to you know I take it with me as much as I can. We went to a picnic and huh that way you know and that way if someone wanted to asked him something you know they can ask him and at first it was kinda hard to understand what the Liberator says, but I guess this new one that they've got now it's kinda a little bit the voice is a little bit better. They've got five different voice and one is Paul something. I think that's about the best voice and then one time he tried the whisper. We have, he has aides that come in and help him cause I have a bad back and he was going to tell on her using the little whisper. I said Gerald you can't whisper with that cause she can hear you say. We had one person and I had left to do something and he just came out and said Mama that nurse called you an old bird and she was standing there and she went.

They don't think these kids know.

He knows everything. He tells me the nurse, she said a bad word on the phone. He tells everything.

That's great

They said you know we gotta watch you. Well no they need to watch themselves. I said you can't get by, you know and it's good because they can tell if something goes wrong so you know

He's gotta a voice

Yes, yes, yes, but he likes to use his and like I said still if he goes to some strange place he doesn't want to take it because he says they ask to many questions.

To much attention

To much attention around

Yeah, what about restaurants? Does he like to take it to restaurants?

No, I haven't took him to one. Um I think he went to McDonald's with the group at school and they went to Pizza Hut. They have teen nights out. He didn't want to take it then. I don't know why, but usually they have this after school program and somedays he might want to take it and somedays he don't. So I'm gonna try it you know I said we're gonna go out for dinner and I'm gonna see how he can order his food.

SH Wanda do-you think that Ashley has any change in relationship with family members after getting her device.

Not really, the only thing that I can think of is her homework. Like when I have to work late and my 12 year old states that the teacher sends homework and she does it on the Liberator and he doesn't really want to help her with it. That's about the only thing that I can think of cause he really doesn't know too much about the Liberator, but it was like from the time she was little there was an understanding in our house that we all pull together and help Ashley and he's probably getting pretty dog gone sick of that Liberator right about now because

He's 12?

yeah

See that's what age my son was although he adored her. Why can't Christine clean her own room?

right

I clean my room

right

I get that too.
When I was 9 I had to clean my room. She's 9 now. Why isn't she cleaning?

I got the other day Jessica can't do no wrong.

He 23 and she's 20 and they love each other.

What kind of homework do they do?

They practice the icons. How to put them together to spell Monday or Tuesday or Wednesday? They are teaching them the days of the week.
She's gonna transfer her daughter to your school I think.

We all are

Yeah, they've got them doing homework on the Liberator.

Maybe I need to sit down and figure out a program and present it to them.

Maybe you need to talk to her and then you can write up part of your own IEP for her at school. This is what you want.

You need to get her out of there.

The goals for next year.

Yeah, right cause they will support her in the school.

They're just modifying everything to get her through in my opinion.

Get her out. I would get her out. I would

That's my opinion. It's a good school district, but in my opinion they're modifying everything just to get her through the grade levels.

I would her out.

SH The next question you're all gonna love. It's about demands on you time. And depending on the device it probably has placed more demands on your time. Bea when Jason got his do you feel like it added more to your time. Do you feel like it was a time consumer that you were trying to find ways for him to access or?

His um no because I mean it's it takes more of my time, but I still so busy trying to um get him to use it you know trying to find some way cause I'm sitting here being real jealous of your guys cause your kids can talk and you know he can't talk and he's just, I'm more I have my days where I get just frustrated because like you said him being locked up. He wants to communicate and can't talk he just can't do anything. He can't write. He can't do anything, but I know he wants to he just looks at you and you know and so it's time consuming but we've got so much love for him and everybody just trying to find this way you know to get him. I mean that pull string we done had the head switches, the light switches and the pulls and the and you know none of that is working, but this string thing you know he can pull it he just doesn't have any accuracy with it you know but we know he can do it cause he has done it. He is doing it just not with any accuracy, but then it seems like when we get to the point where it looks like it's gonna be okay we can work. Then he got sick you know he got real sick and was in the hospital for two months so you know those delays like through us back. It's like starting all over again, but it's not you know it takes time to keep going like come on Jay, come on Jay you can do quicker. He gets to the point where he can pull it and then he'll just keep pulling it and then you know you want him kinda like okay you want to be smart now. So he's frustrated too. He real frustrated.

What did you say he had?

Cerebral palsy

He has cerebral palsy too?

Um huh, but with the brain damage and everything I mean he's

At least with cerebral palsy, I've noticed with my daughter her brain moves faster than her body does and he like you said he know a whole lot more than what he can show he know because he's so locked into his body I mean it's you know. He's so locked into, I mean he just gets frustrated trying to grab things and reach out for things and you know, but his brain is probably reacting about a few second before his body starts trying to do something.

Trying yeah, yeah

So it's like I say it's time consuming, but I don't have a problem with the time.

SH So your okay with the time. Sue, I'll go ahead and hit you cause I know

It's very time consuming. Um yeah, we got to the point in the beginning where I cried Every night and it was like we have to you know I don't I was overwhelmed. I mean it was literally, I was ready to go over the edge at some point and um because it was very time consuming. I mean it was a couple of hours a night and um you know finally I just I finally did just get to the point that it was either my sanity or practicing every night with the Liberators and I choose my sanity which I don't know if it was a good choice or not.

SH It was

No, but I mean it really is still time consuming because if you don't and I think like you said they're not getting a lot of feed back from school so I feel like it's on my shoulders and if we didn't come here for therapy every week they would probably be sitting collecting dust somewhere because you know we get we use them at home and we practice occasionally, but it's not Every night like it should be. There's just not enough hours. So

SH Okay, Kathy has it added a lot of time constraints?

Not really cause I home school, so I spend a lot of time with my children and that just became part of the curriculum and part of the planning and so I can't really say that it has taken up a lot of time.

SH That's kinda a different setting since Kathy home schools. I think everybody else kids go to school. Wanda what about your time?

No time constraints. The teacher has taken it off of me and I really appreciate that now hearing a few of the other parents saying that they didn't have that. She really has taken a lot off of me. you know I'm working and I can't really invest the time and trouble cause if I had to she wouldn't be where she is cause I couldn't do it. So I really appreciate that.

SH What about you Rose do you feel like

Like I said the school helps him a lot

SH Okay

They even program his Liberator so it's no time.

SH It sounds like he can do a little bit of programming himself.

He can really

SH He's telling you things that other people are saying.

He's very smart you know so I haven't had any problems

SH Sandy did you feel like it added a lot of time?

No

SH No, you were okay with that. Mary it added some time to your week I know bringing you child to therapy.

Well it could add more time if I could get all of the input from everybody. I mean if you stop and think about it I want them to get the homework on here which we're not doing so they send home all this homework on top of and I try and do the Liberator time and them I try to it's like I don't have a life from five on.

Home school is easy

I mean to me I would rather have the Liberator doing all this and my time going into this than

and supervising instead of actually having to sit down and do it

yeah, because I mean I think I know she can add. If they get involved if you know what I'm saying, but they're not getting to involved. Mr Bunch is involved. The rest of them aren't.

SH Well we're going to go right into stress now. Has it added or decreased stress in your life and what do you think? Rose what do you think has it made your life more stressful or less stressful?

Well, I don't have to many problems with that because like I have help with him. I have aides that because I have a disability in my body, but now somedays when they can't make it I kinda will cope with some stress. I couldn't say cause you now I have someone there with me to help.

SH And you can't say that the device is really adding stress to your life?

Well now sometimes he can I can turn it off. They haven't taught him how to turn it on, but you know when he gets so much. I have no complaints.

SH Okay, Wanda?

No

SH No, it's not adding stress to your life. Sue I know you kinda already told us a little bit.

Well I think, well it's not that stressful anymore cause I don't let it be, but initially it should be I mean you know I think um the weight of them to carry them around in a lot and I mean you know when I leave here after carrying them just back and forth it's exhausting and I think um the thing that was most stressful was when we trained for those devices. They showed me how to do it and how to us it and I was fine with that, but then no one trained us on how to train the child to use it and you know I felt like I was just like okay I know how to use it. What good is it going to do me? How do I teach? What point do you start teaching them? I think the company when they are selling these things should be selling a package on

seminars for kids

Well not just for the kids, but about how to teach them.

Lesson plans with step by step what to do
To teach the school they are the only ones in the classrooms with it so the teachers weren't aware it. They started out with me. I mean they know

Even though the Macaw is easier they teachers at school have never used one before so you know I sent the book. They copied the book so they have a copy there. I have a copy at home. I mean I think this is fairly simple compared to what it sounds like they are using, but they still didn't know how to use it.

Well, it's not that it's hard to use, but hard- where do you begin? You know

What program are you using with IEP?

IEP ???Clause 20??? But it's like I didn't know where to start? What do you start with common objects or you know

How did you get your device? through who

Well

Like who

Well the therapist at the school first suggested it and they sent us to Children's here for an evaluation and we had it and then that therapist left the school. The one that came in had no training. You know so we got the Liberator and we we're kinda

There was a breakdown somewhere

Well here it is you know and it really the therapist there still don't know. Well I shouldn't say they don't use it but they are getting better, but they had them three years now and um you know they use them for what how many minutes of therapy a week. The classroom teachers aren't using them and um one classroom teacher is pretty open to it, but she said he's the only child in the class that uses it so the other kids think it's a toy so it takes her more time to get the other kids in line. I think that was the most stressful thing. I know how to use it now. It's got a lot of potential. It's a great thing, but nobody showed us what to do with the child.

SH Kathy?

I guess I kinda think of stress in two categories. 1. Your always taking your child. It's like your child comes apart. You have to take your child and then you have to take your child's voice. So there is a stress thing there and the physical type maneuvering. 2. Then I think the training that we got really wasn't adequate. I found myself going through the manuals over and over again and um just trying to find ways to incorporate different at least leading to school situations that we have using the Liberator. Sometimes it's just real difficult. It's be really nice if they could come out with a manual that was Lesson One teaching days of the weeks. Here's what you do, lesson two you know. Lesson two for days of the week. Lesson three for days of the week. Just make it real simple like that and I think the greater stress me because if he's gonna use it. I want him to use it well and then if he's not using it well I feel like that's my fault and I'm not doing enough or something.

SH Okay, Mary your nodding.

Well, I have a question for everybody here. Has any body in here had to program the whole program for the child and not using an IEP, not using 32?

See mine is different. I got help initially cause I can program myself now.

You mean just using the

Yes, that's basically what they teach you in the seminar is to program you own.

Program don't say that

I didn't go to those classes cause Darrel's teacher, she does all of the programming. Even when it breaks and they have to send it out.

What program are they using?

Oh

That Liberator has so many.

TLCIP um TIP, word strategy

I don't know the school takes care of it.

Or are they modifying overlays and doing it themselves?

Mine is modifying overlays herself.

That's terrific.

There's a bad part to this whole thing, but I'll wait until she gets to the question and I'll tell you about it.

Okay, well they have a lot of stress with me, because like she said I want her to use it and I want her to use it well. I want her to be able to use it with the Apple computer that I got for her and you know I'm frustrated because I can't overcome how to use it, where to go?

What program do you like? Does she like

We've got almost every program that there is.

SH She has a lot. She has TLC,

yeah,

IEP. She has PIP.

It comes, gets to the point where it's like does anybody else in the family come first at all? I mean you know I'm a single parent. You work and it's like well when you come home it the rest of your day gonna go into this. It's time, it was just overwhelming you can just be consumed with that and you know there are other things in life besides this Liberator. I kinda got to that point that eventually maybe we'll get better with this.

I don't want to say this is the Liberators fault, it's just the kids. The way they are.

Well, yeah but if there was more support at the school and stuff. I don't mind spending an hour a night going over things.

If you knew where you were going

yeah if you knew where you were going and everybody was working on the same thing and she was actually accomplishing something.

Yeah, I mean the things we do here it's great, but it like great for when your here you know. A lot of the things we do everyday at home or at school.

I know what they mean let's run

One thing it really gives you appreciation for language. I never appreciated the ability just to speak right off of the top of my head whatever thought I might have, because these kids don't have that. If it's not programmed in they can't say it.

Another frustration of mine is we met the speech pathologist at her school at the IEP meeting. She's not interested. She don't have time for the Liberator. She's either fed up with it or just not interested.

Okay,

That's not okay

I know, I've asked why can't you take the training not this year but the year before. I don't have time. I'm like okay, so she's not even interested.

SH It sounds like the devices have caused quite a bit of stress in a lot of families.

They could be a good thing.

I wouldn't mind spending the time if I was accomplishing something, but I don't. Don't get me wrong I think you guys do great with her and she loves

SH You can say whatever you want to.

But I want it to be incorporated into everybody's doing the same thing with her. It's not I'm gonna sit here and let her do what she wants for twenty minutes at school you know. It's frustrating.

SH I might be wrong Beau, but I guessing the frustration you might have the stress might just be in getting him an access method.

So it's just finding the way

SH That's probably the biggest stress as far as the device goes for him.

I was just curious where do your kids go to school at? I mean from day one Jay's teachers or therapists

shocked me terribly

me to

they have just

my daughter is mainstreamed

Oh, they're mainstreamed?

No, mine isn't

Mine is

Mine isn't either

She goes to Francis Howell out in St. Charles. One of the best school district out in St. Charles I can't believe that. That's why I'm just dumbfounded. I never heard of such. The teachers are so, I think the teachers

Oh, their teachers are wonderful. I don't mean to like bad mouth the teacher, but I think that one thing the teachers didn't have training on the devices and there's like I did this at a classroom in special school district where all the kids where using them and it was wonderful, but you know I can't really blame the teachers. They can't be spending their whole day with just one child you know there's other children in the classroom. I mean I don't know what the answer is. The ideal thing would be to get a classroom with kids with just Liberators and then their classroom planning would be around the Liberator, but you know that not what's happened.

My mom says that there's some place out there that has a class with just Liberators.

They do have a class just for the Liberator.

I don't know where it is.

Well when she gets to another question like that you can call those people the 800 number on the back of the Liberator. They'll tell you they got a training class and they dates that they set the training class up for. They told me when I called it, cause I didn't even know how much they dog gone thing cost and how would you get to a question on there.

For the parents, right?

No, my mom was talking that it was the kids in a classroom setting just Liberators and that's all they got.

Where did you see that?

Well you know where Darrel goes they had like three or four kids in the class. They'll have a whole bunch and they give the teacher time to spend and then they have helpers or assistants and they have time to spend with these kids and um you know like those teachers do it. I mean I haven't you know they do wonderful.

That's why I was wondering if she was a state school where, but this mainstream.

My daughter is. She goes to regular school.

You child is not mainstreamed and that's why I don't understand why the classroom is that big that the teacher don't

Well there's 6-8 kids in the classroom.

There's what

6-8 kids in the class, but the kids that are in each classroom. There's a variety of disabilities in there you know.

I can understand that, but is it any aides or assistants in there to help her?

One of the classroom has an aide in it.

You kid is not stationary to one class, she moves? Is that what your saying?

Yeah they move.

Oh I would give that company that gave you that device. It would, I think it would be their responsibility to get somebody out there to your house to teach you how to use their devices for all that money.

I agree

Or the school

SH Terry can't get around that much

There's only one person

Well I would think they could get somebody.

I've got a question here. Does anyone's kids here go to a regular school district.

Does Wendy go to a regular school district?

Maybe, she's mainstreamed.

Yeah, mine does.

In a regular school district? She don't go to special school district?

No, no Wedgewood I think is a regular school district.

Susan maybe she's in the wrong school. She in a regular school maybe.

I don't know

It's the frustration. It's the teachers.

The teacher took the training and he's gungho about it, but I don't think the school districts backing him up that much. I mean he's a good teacher, I just don't know. I don't really know where.

SH We talked a little bit before about taking your kids out into the community so we'll go back to that a little bit. Do you think that their having the device that has also affected your ability to take them out to restaurants to do like social or recreational things? Is something where they take their device or where they choose not to or has it made a difference they're having the device?

When Christine uses is they are still looking at me to translate what they can perfectly well understand themselves.

SH Okay

And I think that you could particularly understand her and what this whole device was for was because Christine could talk. It was just to slow down her speech. The machine says it and then she says it like the machine does and even thou she does that they are still looking at me to translate what she is saying which is perfectly understandable.

SH So its

Well not perfectly, but understandable.

SH So it's really not made any big difference her getting into the community.

Frustration, I want to tell these people to listen to her.

SH Wanda have you noticed?

I haven't been taking my daughter out with hers yet. Hers is attached to the wheelchair and I don't have a van that can take the wheelchair so I just leave it at home.

SH right

So I haven't been able to take it out with me.

SH Okay, what about with Darrel is he

Yeah, I have took him several places with his Liberator. It helps him to say what he want to say, Instead of me asking him or looking for eye signals or trying to pick up what he wants or anything or so. It helps a lot and he can say what he want to and he knows how. Well they teach him at school what to symbols to put together to come up with one word and um and so he do good.

SH Sue, I know your have gone out with their walker talkers.

They love them and I mean they would use them. People are receptive to them. The main problem is that they can't program what they want to say. It's back to predicting what

That's what I couldn't understand cause with Darrel they have um they teach him, like you might have an apple and a sun and they say you put those together and the device says sunny. You know and they teaches him cause I don't even know some of the words. I have to look in the book to find out what word to get what you know, but they teach

No, they're real open to them and they love using them. The Walker Talker's memory is so small that you can only program a short conversation in it. That's the big down fall to the Walker Talker cause we got that because the Liberator are just to heavy and since they are ambulatory. Chris weighs 30 and Gina weighs 40 pounds or something like that. So they're just to heavy to carry.

Well, Darrel's fits on his wheelchair.

You know and they are so expensive. It's like they take off in different directions and I stand there holding two Liberators yelling cause it's like you just don't have that many hands. So I means

Two of them god

So it's the weight of them, but I think that if they weren't so heavy and they could get access to it easier they would use it a lot more cause they love using it. They're very social and they would use it a lot more.

You see these marchers in the band and they have these contraptions around that support the device. Do you think there could be something they could invent.

They would topple forward. They to little.

SH Has Jessica been out in the community much with hers? not a lot?

No, I don't even say that and I know that I have a van with a lift, but I have a stroller and it's easier right now. Pretty soon I'm going to have to go with a wheelchair and stuff like in the stores you know the stroller is real nice. I need to slow my life down. Okay, we've got to take the time to unload. She's about ready to out grow the stroller, but we'll see. She can talk too, I mean if we go to like a restaurant where there's a waitress they will listen to her. So if she's got the Liberator I know that just the couple of times we took it out people were looking at me she sat down at the gift shop. What does she want? I could understand, I want a bag of plain M & M's.

You know with Darrel's Liberator it prints out too. It prints out what he said cause like some words you might not understand and you can look at it and it had it printed out.

SH Kathy have you taken Jessie?
No really in the public situation with restaurants and stuff like that, but with a lot of home schooling situations where I know that he's comfortable with people. We've had talents shows and he's gotten up on stage and read books and um like I programmed all of the animal sounds that we could think of and then I would say a dog says.... and he would go bow wow, a cat says.... and he say meow and mothers the tears were coming down. People are very impressed when they use them correctly.

Do you only home school your son?

SH Would you like a few more kids?

I could have a Liberator class.

SH I know somebody mentioned church, that their child takes theirs to church. Is that Darrel?

um huh

Christina would take her to church and she play with it.

SH That what.. you could hear the church?

She signs to me in church so she still can talk. Heaven forbid she not be able to express herself. I mean she tells me it's time for Jesus.

They always call Gina, Christina in training.

SH Okay we're gonna switch. Okay our question now is what have been your greatest concerns in working with professional and actually getting your child's AAC device. That could be like the professional at school or if you, whoever it is you know that tried to help you getting the device. So you can think about different things like it took a really long time to get it. They didn't help me get it right away or you can think about you know whatever comes to your mind. Sue

Um I don't think that there was a lot of problems in getting the device I mean the school suggested it and they sent us here for an evaluation and then they were evaluated and it was recommended and then I did go see one I think I went to see one first. I don't even remember any more, but um and it really the time didn't take that long to actually get the device, but we had to go through training before we could get it and that took a while to set that up, but really as far as getting it, it didn't take to long. I think that everyone was really receptive and open and I didn't think, I thought we had a lot of help in getting it.

SH Okay, Wanda you just got one fairly recently. Did you have any concerns in working with the professionals in getting yours.

Yeah, when they first told be about it um from the time they first told me about it I had to fill out tons of paper work. It took about half of a school year for me to actually get it. First of all, I didn't know who was authorizing her to get it. This had to be authorized through somebody in special school district. I didn't know who to call to inquire about it um the teachers totally took control of the whole thing and took it away from me and when she got it. It just arrived, the teacher told me about a week later that they had the Liberator and I was really upset about that and I wanted the books and the Liberator right then and they told me no. It's gonna take us about a year to learn how to use. We gotta keep it at school for about two or three weeks and learn how to use it. I was really upset about that. I had to call the company find out how much it cost, who funded it, who funded my daughter for it. How did she even get it. You know it was a total breakdown from that point.

SH So you really felt like you weren't included in it at all.

I was not included in anything at all except for signing my signature and fill out the paper work that we want to use in programming it. After that, once I gave them the okay to go ahead and get it for her I didn't have any, I don't know how she got it. I don't know who funded her for it. I didn't know how much it cost. I didn't know anything. That really pissed me off. I called that company and I told them: I want to know how much this cost and I want to know who authorized her to get it and I didn't have any training on it at all. All they told me was that they thought this device would be perfect for my daughter and I said okay fine go try it. Sent me paperwork and I filled it out. After that, it took about six months and all of the sudden people calls me two weeks later and tells me that her Liberator has arrived. I thought what is the Liberator? By that time I had forgotten all about it. It was a total breakdown and that needs to be changed. It really does cause that company got $10,000 for that Liberator. Where they got it from I didn't know at that time, but I felt like I should have been included you know some type of in something, but that company got a lot of money for that and all they did was ship it out. That was it and they just dropped it in the hands of the school and thank god I had good people at the school that did it, but once the school got it, it was theirs. They acted like it was theirs. Oh, we're gonna keep it for two weeks cause we want do this and that. I thought I didn't even get the thing for two weeks. Why didn't your want to come up to the school fine and right up to this day I don't even have one book on it. The teacher has all of the books on it. So when I say they took it from me they actually took it from me.

Who was it paid for? Was it paid for your daughter?

It was paid for my daughter, for my daughter. She is the only one in the school district that has it and that's why they went crazy over it. See this is an experiment for them to learn how to teach the next child that gets it. So they totally took it from me. I didn't like that at all.

And you still don't have the books?

No, I have no books on the Liberator.

I've gotta get my books back.
Well I really not cause it's helping me in a way cause they're teaching her while I can't really invest the time when they're teaching her. So I'm letting them go on and do it, but I really got upset about how it all

that you weren't informed

SH That you weren't there. You weren't included in the decision making process.

I wasn't included in the decision making process at all. Even when they got it, I thought we'd teach her for maybe a week at home. I'd have some type of control, but I found out that to be the case in everything her wheelchair, her walker all that. They totally took over and tried.

SH Not a real family centered approach I guess.

No, not at all.

The school did it all this for you?

Who paid for all of those things?

Medicaid paid part of it and then they got funding from some other source. I'm not really sure. They just totally took over, it's like, but in a way it's good you know what I mean in a way it was good and in a way I felt bad cause they really didn't

include you

Include me and it wasn't that they didn't need. I think they really didn't need me after I had given my okay.

Your signature.

And they just took it from there and they acted like it was theirs. When she got her wheelchair, we fused about what kind she wanted. Her therapist thought she needed this kind and I thought she need another kind so we argued about that cause they wanted to try to get her funded for this one and I said no I want her to have this one. You know they just totally, they try to take too much control and not give it back to the parents and what they want your daughter or your child to have a specific device they really push that company. I don't like that. They push the company that they feel is best. They're not pushing, okay I feel that this device is best for your daughter. Here's the company that we're gonna go through with you not knowing that there's five other companies that you can go through.

Is there any other company?
They push a certain company for those devices.

SH This woman here has one that's made by a different company.

Of course, then I have just the opposite because I have the McCaw through here and I was shown different machines. Which one do you think would work? This is how much this one cost and this is how much this one cost and it was up to me to fill out the paper work to get my funding. I mailed it to the place where I was getting funding. They contacted me back. They sent it to my house and then I brought it here and we went over it together. It was just the opposite for me.

I'm surprised they owned all that equipment. She goes to regular school right?

Well, now she does this year. This had been in the making for three or four years now. Special school district now that they have. Yeah, they have pretty much took over. I don't like, like I said and I'll say it again, they push certain companies and I don't like that. You know when they feel that this device or they like this particular company they will push for you to get the funding for that particular company.

That's where you know what ??downs they look unresolved????

They hate me.

Well the company that we went through it was like once they knew that we were getting the funding then everything was as easy as could be, but they um even when we had a breakdown with one of the device is was kinda like they didn't want to fix it or they kinda kept try this they didn't want me to send it to them because they though it was going to cost money. It was gonna be funded to pay and once they knew that everything was fine, but it was like you know they make I feel like they're more worried about where the money is coming from then about backing up their device afterwards.

When you send yours back how much does it run you?

I think just to mail, to mail it I think it was like thirty something dollars you know just to mail it and then you have to insure it and they don't pay for that

You've gotta pay for that out of your own pocket.

And that's why they were discouraging it

How long is the warranty on these things?

A year
And then you've gotta pay for it yourself?

They have a warranty for a year on a $10,000 machines?

Yeah, it's like $180 for them

They want like almost $200 a year for a machine to secure your warranty.

See they know more than I do.

We read all that.

You didn't get your booklet.

We get all the junk delivered to us.

SH How was it for you Rose cause you son

I had no problems when we found out that Darrel was gonna get um basically it was a Light Talker. The teacher explained everything to us and um they found the funding. When he got to the Liberator they had a class and they said if you wanted to come and they had two that you saw before you even got it and they showed you how to use it and how to program it and things like that, but huh and then the teachers and every time and even for every device that he needs the teachers will call me in. We sit down and talk it over and we think do you think this is best you know and I have no problem with that. Then they um find the funding for it.

SH Did you have any frustrations Kathy?

Not really

SH Sandy?

They recommended that it would be a good idea and that somebody named Sheila was in charge of getting it all. It all just kinda happened. I didn't feel like it was a problem at all.

SH How about you Bea? I don't know if you remember who recommended Jason.

The school, the school did. We called and made an appointment over here. Fortunately, I just never had a problem getting anything I wanted. My job pays well and I just, I mean no matter what it is I want. I want it. I get it. I put in for it and I get it. I just never, I've just been fortunate. I've just got a good job. I never had any problems with anything. I mean we grew out of chairs, out of bath chairs. It doesn't matter. I mean from day one and he's 10 years old and I been there 15 years and so I get what I want. It doesn't matter what it is he needs. I mean I'm really great full, you know don't think I'm not. I really great full. I don't have to go out and look for any money. I get everything I want.

You deserve it though. You've been at that job for 15 years. You deserve it.

You know I don't

SH Well it sounds like everybody has had a different experience actually with working with professionals getting their devices so let's talk a little bit about what you think the roles should be. What do you think professionals should do in working with you in trying to get your child's device? Wanda why don't we start with you since you didn't have a very positive experience. What do you think should have happened? What could have been different?

I think that when I was calling and inquiring about how far along they were coming with the Liberator I shouldn't have ever forgotten about it. It shouldn't have even gone on that long. Whenever I would call the teacher would always say I'm going to call Barbara so and so and find out how the service is coming. I should have known who these people where and maybe that's my fault too. I'm not going to totally blame it on them, but I should have been kept updated. I should have been put more in control of what's, where the funding was coming from you know all this and the other. That's just they way I feel. I should have been put more in control of the situation. When the Liberator was sent out, it should have been sent to my house and not to the school. They should have been able to call me a week later and tell me that it was delivered and how that got mixed up when I called the company. They told me that the lady that was responsible for they ordering it and approving it told them to send it to the school. They apologized for that, but that was probably it.

SH Anybody else that thinks that something different should happen?

I think it would have been helpful if I could have seen other children using the device.

Yeah, definitely that would have helped

It was given, it would have given me an idea of what the potential is because I mean I saw the device and I saw how it worked, but I never saw another child using a device. I think that would be real helpful to anybody to see how it could be used and how it could benefit before you get thrown into that.

I never felt like my therapist really had a handle on it. I thought kinda they were learning as they went along which wasn't their fault. They just didn't have the experience. It would have been nice, I don't know how long Liberators have been out, but it would have been nice to know somebody who could just flip that open and just go okay ba, ba, ba, ba, ba, and this is what we're going to do. Most of the time they we're going let me get the manual.

With mine is being more simple because we kinda had to read the book together and see how to program it. You know that's probably the only thing. They didn't know it either.

Well, I've seen the therapist
in the hospital are real ??humble??, but in the schools the professionals in the schools are not trained at all and I think that's one of the biggest down falls. You know I mean I don't know what the answer is.

I have a question, would your experience and with the different teachers at school do you know how often they're updated on special equipment? on all these communication devices?

SH I think it probably just depends on the individual teacher. Ones that are really interested that have a lot of kids with devices might take more of an interest. And some people aren't sorta technology afraid. They're kinda scared by computers or anything that look technological and you know that might just kinda put them off. So I think everybody is different. Certain teacher obviously Wanda's daughter is in the classroom where her teacher has taken a big interest. Her teacher is actually the one programming. I think if you have a teacher like that, that's probably wonderful. I'm not supposed to be talking, but that's wonderful because your teacher is probably with your child more than any other person. More than a speech pathologist, more than and you know and that's why I was like Kathy being the teacher. She's her child's teacher and mother and that's probably why he sorta made that big booming once he started getting the idea that this is speaking for me and I can get things you know. That probably was a big advantage having his teacher, his mother, the interested party right there all the time with him.

How do you find the time to learn how to program it and everything plus school.

Late at night.

I bet, I stayed up quite a few late nights waiting for the 800 number to call me back.

group laugh

Did you ever have a time when they didn't call you back?

I've had that before and it's like okay, two weeks later they still haven't called me back. Am I still supposed to be sitting here with this Liberator?

I think we let those companies that are manufacturing these off the hook to quick.

SH Okay, go ahead

They manufacture them. They ship them. That's it. They're not doing anything else and the people that are spending $10,000 for these, for this equipment should put more responsibility on the manufacture to send somebody out to these people's home for an extra thousand bucks or whatever to train these parents on how to use that equipment.

I agree

I think we let them off the hook to quick.

Actually I think part of us as parents fault. We can like Christine the variety club helped us and you know I'm not calling back to the Variety Club and saying well the company didn't do this or the company didn't do that. They don't know once they've funded for us. All they are really asking for is a picture to using.

They don't care where the money comes

All talking at once-----See I called and them real good and I told them don't you ever.
I'm not talking about the company. I'm talking about the people who give you the funding.

That how come we're coming here for therapy because the company never you know I mean I was stressed out I couldn't handle it and so the funding were sent here for therapy to help get us through that because the company doesn't. I mean they give you that one or two day training and it's like

I've taken that training five times.

They did tell me though that they would send somebody out to my home to show me how to do it. I remember that about the Liberator. I don't know. Did you guys got a different device? Well and I

No I got the Liberator

You got the Liberator too?

Well then the person that did the consultant I mean I think that if I call her I think that she would probably come but she's also the kind that to me she to the other extreme. She thinks that we should have you know lists next to every object in the house and where it is.

???She professional if it's the same person I mean??

Her ideas are right, but realistically she told me to take the Liberators in a little cart and go to the shopping mall and I said so I have this little cart with two Liberators and they take off and where are they? While I stand in the middle of the mall holding the cart I mean realistically it just doesn't work. The idea sounds great, but how many people you know are going to have tapes of lists of everything around you know we don't live

In every door way.

Yeah, I mean you know time lines and realistically it's
Do you guys every question the prices on some of this stuff? Do you know what kind of computer you could buy for your home for $10,000 or you buy a car for $10,000. Not that I'm not great full for it, but it's just like because somebody else is willing to fund it the price goes way up.

Mine is the small one and is was $1,800.

The vendors are the biggest rip-offs that there are.

Computer is half that amount and I have much more stuff in her computer than could ever go in her McCaw. The computer has CD-ROM and everything. You have five hard drives in the computer and it's half of the cost of this voice box that she uses once in a while.

SH I think right here we're talking about cost and that's probably something that people feel like bringing up is that these devices are pretty costly.

Just because my child can't talk means that I have to pay an arm and a leg so that people can understand her. Well that's not fair.

But you see that in all the catalogs, I seen puzzle the same $6. puzzle just because somebody put wooded pegs on it's $27 and you just really question their heart. You know what do they think about they want to make a buck.

They want to make a buck it's obvious when they're dropping those computers off it is.

That's because the insurance will pay for it.

That's right (Everyone is talking) They're all paying that price and I still think that the purpose of this is so that these people can know out here we let the companies off the hook to easy. The people that are purchasing these equipment need to put more responsibility on the company.

yeah

That's just the way I feel about it. It's just too hard on us

yeah

That's right.

And maybe the people who are doing the funding should do a little more shopping around.

That's right.

Maybe the market's more open.

That's what I meant when I said that they are promoting one particular company.
Prentke Romich is the only one that gets promoted. It's kinda like UE. Where else will you get electric if they shut it off?

SH If you could tell professionals how to better work with families when trying to identify devices for children. What would you say?

I think we just said that.

SH One thing that I'm hearing is that you would like to see more device. You like to see actual children using devices. You would like to be included. Okay, is there anything else that we have missed out on?

The materials that they put with the devices should be more user friendly

SH okay

And accessible to us before they are purchased to see what they are all about.

SH okay, anything else on the mind. Did we get everything on there? Okay, how if at all are the values and the beliefs of professionals that you've worked with different from yours. If so how did these differences affect what happened when decisions where being made about the devices? Do you feel like any of the professionals that you worked with have a different value system than you do and they may be affecting their decision opposed to your?

That's a tough questions. I mean really if you think about it

I remember I had this speech therapist when my daughter got ready to get her wheelchair and her and I didn't click um when I say click we really didn't get along very well and when it came time to order the wheelchair my daughter wanted or I wanted for her I wanted to see the battery operated wheelchair and they had a different one that wasn't battery operated. Well, she felt that my daughter should have the lesser expensive one and she said because it was lesser expensive. I found us going back and forth cause the money was not coming out of her pocket, but because she was the therapist it took her signature to get my daughter approved for it. That came into play, but when you say different ??pigments?? or whatever comes into play whether or not that therapist and parent is interacting because you need them in order to get approval for this and if you and that therapist is not connecting. That therapist, actually it's in her hands to prescribe something that's not even to your daughter's or your child's benefit and me and her fought over that. My daughter didn't get the right wheelchair that I wanted her to have until she went tot he next school and that teacher said I couldn't believe that she wouldn't let her have this one. Last year she was ready for it.

SH So it sounds like again it may be a personal conflict, but again maybe not the family centered approach where they're listening to what the family wants.

I think we were depending on the therapist to help us know things that we don't know.

There you go

And I've had that problem

And it's that trust thing because we didn't plan on having this child so we didn't study on how we were going to raise these children and you guys are working with them and you know we're expecting the professionals to be able to help us. Maybe not make the decisions for us, but maybe guide us in a way that we're going to be able to make a better decision.

When you say guide you. I could tell you that um I'd like for you to have that tape recorder down there on the floor and by me being the therapist you trust my judgement.

I'm going back to where you said instead of promoting one company. Let's show us all five companies and then guide me in a way. Tell me why you think this company is better than the other four.

Well this is what they did. They had five wheelchairs laid out on the floor. We walked by each one and then she told me after I got done walking and I picked the one that I wanted her to have. She said well, I think she should have this one. After we walked through all five I really didn't have trust at that point and because she and I were exchanging words I got down right upset about it. I said she's getting that one, okay.

And she said she's getting this one

And so then she got my husband involved and he sided with her cause she's the therapist. She know more, so he sided with her and she got the other wheelchair, but the next year she got the other one that I wanted her to have.

SH So it wasn't so much a different value or belief, but perhaps you were having, you and her didn't click.

Right, and that plays a big thou. That plays a big part

I think that's gonna happen.

Yeah, it's gonna happen in life.

Sure

I had that happen

I didn't that problem so much with therapist, but I think the consultants or the company would just the biggest salesperson there ever was. I mean they were pushing that product so badly that when I would have a question like what about this thing. They always had these answers. Like I said they are not always realistic in everyday living. It sounds good. She may think it's a great way to go about something.

SH You were kinda feeling like you had to be super mom there through all these things. Oh yeah, cause I mean you know cause this is their whole life, but you know

Do they really have kids? Do they make these devices for their children to use or do they just make them to make money? you know

I remember I had that problem with Darrel. They wanted to get him ah electric chair and I think I went in and watched him and I think he'd do great with it, but the therapy, she don't think that he's ready for it and ah he got one it's paid for. It sit that a whole year and he out grew it, so what they gonna do with the chair? Like I still think that you know he could be able to use it, but she don't think it's made for him.

Like do they ever like have an exchange program that as they go from one thing you know your stuck with this device.

It depends on who pays for it

Your stuck with it you know I mean they don't kinda have an exchange program to update them.

You can get credit for

Then it's like okay this is better, but what do you do with this $10,000 piece of machine.

We have a

They should give you a rebate or something or trade in.

They could take it back. Clean it and sell it at cost.

Recycle some of the parts.

Absolutely

We are with my daughter.

Everyone is talking-----about being reversible.

It was a misprint in their magazine. Their catalog that they put out.

SH I'm going to move you back into communication devices. I'm going to ask you one more question and then I'm going to give you a chance to say whatever you think we haven't covered. You can bring out so I'm just going to have you think about the communities that you live in cause everybody live in the St. Louis community, greater St. Louis community. Think about the kinda area that your live in and your child and his device and tell me if you think that there has been any kind of effect. Your child having it within your own community, that could be like your church community, your actual your street or your extended family ah just kinda think. Sue I can start with you I know you live in "the hill" (Italian) area. Have you noticed any kind of differences with your kids and their community relationship? Are they?

As far as the device goes not really they're social without it. Like I said we don't, we really don't use it in the community because it's just so clumsy and heavy. Um I think people are real interested that are around it and I think that they are very receptive to it and they do. I think that people would be receptive to it and they do think it's a great thing.

SH Okay, so they have more sorta positive things.

Yes, I think so I haven't had problems with it so far, you know some people are a little you know taken back, especially other kids are real interested not just to sit and talk, but they are actually

There's something they can learn.

They're talking back and forth with them you know using it.

We haven't been out in the community, but in our home school community with activities and things like that and the talent show and things like that it really changes people's impression of Jessie because he doesn't speak and doesn't walk. They think he's has nothing up here, but then when he says something intelligible they're like oh my gosh. So I think it's really does a lot for my self esteem or his self esteem or something like that.

SH Okay, Rose what do you think with your community?

I don't have any problems. I think Darrel he just fits in anywhere I believe you know.

SH It sounds like he's kinda assertive with his device.

Yeah and he's you know very alert and a lot of times he'll be outdoors and he usually don't have it and then when he does have it, I think it draws a lot of attention. Everybody's curious and they wanna know what he's gonna say and then he just kinda gets tired, but I don't think that he has any problem with that.

It's the same with me as her. Ashley in the girl scouts and they all wanted to know initially when she got you know. How to use it and when she's out on the porch kids come up from all over the place and she just zooms up the street in the wheelchair with kids running behind her and she's pushing dust on them. So I mean she's just like she descried her son. She doesn't have a problem with that. The community they really like her. The kids that don't have a disability they are really interested in what it's about and they really like her and it's

The kids ask more intelligent questions than the adults.

Some kids can get in there and program it a lot quicker than we do to.

They are so computer friendly at school.

Yeah, your right. That's a good point.

SH Okay the last thing that I need to ask you is there anything else about this subject that I haven't asked you about? Is there anything that you really just want to tell you know either about professional or family life or anything relating to a communication device? Anything that you feel like you want to unload or just want to say that you think would others?

I think it's just let having the parents see other kids, not just professionals you know other kids seeing, seeing other kids using it and then getting some support from the company afterwards.

Or a parent support group where parents can learn from other parents what's going on with other kids.

Maybe get ideas from that.

This has been help for me just to hear somebody else say we don't use it much.

Or to hear her say that the teacher's involved. I'm going wait a minute. I want to talk to this teacher. I want to figure a plan. Something that I can take to my teacher.

Maybe they should get into the schools more. I don't know what the answer is but you know

I think there is a breakdown

A classroom, but maybe the school districts or something.

There's a breakdown between the times that your looking at the computer and the time you actually get it. Somewhere in there like with them they got dumped with this computer and like the one therapist that initially initiated left her job and nobody actually picked it up to help her out with that. Sounds like a breakdown and that should be prevented some type of way. The person that initiates this like in my case this person named Barbara so and so and the school district they need to follow through with that. Just don't sign your name and shot these computers to these parents.
When you say initiate, I don't even remember who initiated.

Me neither, I don't even know her name. Whoever initiated it has responsibility to follow up with you guys and try to... you know there's a break down somewhere between ordering it and getting it and then learning it.

Maybe the companies I know I guess they still have just one rep for this area and she covers a wide territory so you know if you want to get some training on it. It's far and few between. To me there's a lot of Liberators and speech devices in one area that they need maybe a couple of people.

As much as they cost they should have more than one representative.

For $10,000 dollars they should have two reps just for Liberators.

They should hire their own speech pathologist there that just necessary can work with the parents and stay with the parents.

And give you guys support.

Yeah, cause there's a lot of movement in therapy. You know that like we're saying the therapist probably schools moves on to a better job.

Well, down sizing at the school.

Yeah, or down sizing.

I think what I said before about written materials I know that Sandy went to a conference and um she had brought back this book and she let me take it home an look through it. It was actually things that teachers had done. Like it was using books that I recognize, The Very Hungry Caterpillar and it was almost like little lesson plan of what this teacher did with The Very Hungry Caterpillar and to me as parents I was wow I was really neat. That's something that I can grab a hold of

I need a support group of some kind.

Or even just the materials, a newsletter that would be more people input of what they've done for their child with the Liberator and that a way they spell it out for us.

You know they just gave you that one day training. Like I said not just train me, but train me on how to raise a child.

Focus Group with Parents Having AAC Devices

April 17, 1996

Nancy Dunn, M.S., C.C.C., Moderator
Arkansas Easter Seal Society

Summary Background Information

Type of Group: Focus Group with Parents of Children with Devices

Date Conducted: 4/17/96

Where Conducted: Augmentative Communication Lab at the Arkansas Technology Resource Center at Arkansas Easter Seal Society.

Number of Persons Present and Roles: Bonnie Holmes, mother of 5 year old son who has cerebral palsy and uses a Delta Talker, **June Simpson** and **David Simpson**, parents of 7 year-old daughter who has schizencephaly and uses a Liberator.

Logistical Issues: Three more parents were scheduled to attend. We scheduled approximately 2 weeks before the groups and called to remind a week prior. Those present are all Caucasian parents who have adopted African-American children.

Synthesis Statements

1. Family Expectations
    - Family wants child to communicate needs to others

2. Impact of Devices on Families
    - Reality of technology is confronted when family must learn to use AAC
    - Family assumes role of transporter of device
    - Family assumes role of training others to understand and use device
    - Entire family has to be involved in learning to use device
    - Alternative communication system may be used in home, while electronic device may be used at school
    - If device not used regularly, family must commit ongoing time to learn to use
    - Stress sources vary:
        5. Deciding what language to use at school
        6. Deciding where to house vocabulary on device
        7. Difficult to use device at church

8. Difficult to transport device across recreational settings.

3. AAC and Community
   - Device causes others to inquire about it
   - Stress generated if device is carried into public settings
   - Public displays mixed reactions to devices: curiosity and shying away
   - Families vary on utility of AAC devices in community (difficult with transportation versus enhancing communication)

4. Working with Professionals
   - Use of jargon inhibits communication with parents
   - Families need information regarding devices
   - Families need hands-on experiences
   - Device selection should be linked to future communication needs (cost issue)
   - Vendors should provide information regarding critical features of devices
   - Families want information on range of devices
   - Families recognize that professionals may recommend devices they are familiar with due to vendor availability.
   - Professionals should be sensitive to parental expectations for child .
   - Balance between immediate and future needs should be considered during decision-making
   - Professionals should recognize that families have no background in parenting children with disabilities.
   - Repair time results in child being without device
   - Some children will already be familiar with technology which will facilitate decision-making
   - Child preferences for devices are influenced by early experiences
   - Professionals should communicate their discomfort with a/c to families to enable family to have choice regarding therapy alternatives.

Transcript

ND What I want you to do is ah to go around and introduce yourself.

David Simpson

June Simpson

I'm Bonnie Holmes

ND I guess we might want to make a comment right now that both these families, two different families have adopted African American children. So they are truly a multicultural family. Okay, I'm going to ask you a few questions. I want to start with you.

okay

ND What were your goals or expectations for your child's AAC device before it was received?

Um, the goals would be to for her to communicate more readily or easily so that people not only in the family but outside the family could understand her needs and wants. And just what she might thinking you know the different things that kids talk a about.

Well basically the same thing. I just looked at it as Taylor's way of communicating in the world and get bigger and just a way to communicate in everyday life is whatever he needs. Just his voice.

ND Let's explore in what way if any the AAC device as affected you family? Do you see if affecting roles which you might not understand?

It made me have to get into technology that I never dreamed about and um I you know just the computer and things that I just didn't think that was going to be part of my world. Which it is very much part of my work now.

Well with Marcie's device she's very fluent on it, but she's not able to carry it because of the weight we have to make sure that it's transported and because a lot of people are really insecure being around it or intimated. We kinda really have to big effort to put them at ease. It's not going to break you know. It's all right if other kids touch it. Give her time. Pay attention so you can understand, cause it is a mechanical or computer voice and so a lot of it's teaching others to be patient and to give her time.

Now when she understands it better than we do.

ND Do you think it would affect the relationship with other or it has affected relationships with other family members?
It certainly involves the whole family and everybody know about how to run the device and everybody has learned about it to some degree. Of course our family is different because we have adult children who don't live in the home and then we have a five year old who is in the home that was adopted. So it's just my husband and me and Taylor, but I'm sure if there were other small children in the household it would certainly involved everybody.

It really has not done that much in the family because Marcie is so expressive with her eyes and even though she's nonverbal, she's vocal. For the most part she uses the Liberator for academic and telling jokes really more for people outside the home.

ND Do you think it has affected the demands placed on your time?

Oh yeah, there's a lot of studying, because I don't use it everyday like Marcie does in her academics. A lot of times I have to go back and look something up or I have try to figure now where is that and yeah it's a lot just keeping up with it.

It's time consuming to learn about it and be involved with, but Taylor is using his more in our family situations where he's not in public yet he's just at Easter Seals but, we he signs for it and he has access to it all the time. So he's using it more and more as ??time goes??

ND Do you think it's affected the levels of stress that you currently experience with the AAC device?

Oh I think so, if nothing else than making sure that you have the technology that your child requires that, especially in the school situation. We had a device last year that the teacher wouldn't hardly mess with because it was so complicated and when she got her new device and had icon sequencing. They're just much more ease and tried to go through a lot just trying to get the school to use it um you it just so intimidating. So yeah it's very stressful and to make sure that things are listed on it she might want to tell at school. Trying to figure out where to put if and if it's already in there and if there is new software that would be better for her. It's a never ending situation and one device does not go in all areas. The device that she has now is wonderful academically, but because she can't carry it then it's hard for her to use it at church. When we go to camp, nobody wants to lug around something that weighs 5 pounds and costs as much as it does. So it's almost like you need several devices.

You know he does have a new device and even right away we've been able to mount it just last week on his locker so that can have it as he walks. It's on the back of the walker so he has to stop and turn around, but at least it's with him. Also we have just gotten a mount for his wheelchair so that has helped a lot. Having the AAC device all the time.

See Marcie is ambulatory and so

ND How do you think it's affected your relationships with others, particularly in your community.
It certainly gets people talking to ya.
Yeah, when we go into a restaurant and there's that Talker up there on the mount in front of the wheelchair and all of sudden everybody wants to know about it. So I think I should get a commission from the company. I sure do tell about it.

Marcie doesn't carry hers with her into a lot of different situations because she is, she can sign which is she's just a little bit vocal, but it's more stressful for me when she has it because of the fact that we have to carry. People are inquisitive about it, but I also find that they tend to shy away from it because it is a device used by someone with a disability.

ND How do you think it would affect your ability you kinda answered to take your child into the community. Like to eat at restaurant or other social or recreational activities?

You know for us it adds to it. You know we take Taylor everywhere and um this way he can communicate better when we're out in public and

It's just too bulky for us to mess with.

ND What has been your greatest concerns in working with professionals in getting the device?

In getting the device? Understand what they want and I think the biggest thing was making sure that we understood exactly what they were saying and making sure the devices that they were suggesting were the right device for Marcie. A lot of times they're using technical words, definitions or words from a particular corporation and your trying to figure out now what in the world are you talking about.

Yeah, I really think and I know that they're trying to sales rep and stuff like that got to find the appropriate thing, but I almost think that for a new parent or new device when you've never had any exposure to that. That you almost need to talk to the representative of the different companies and let them demonstrate the devices because when your new to this I mean they all sound the same. You don't know what to expect from them. You have no exposure to any of them and ah I really think that would be a real advantage to parents.

I think that another problem is the cost involved. When Marcie got her first device it was just astronomical amount and because of her abilities and the fact that insurance would most likely only pay for one. It went, when they bought it was more for kinda down the road. Her future, that she's gonna be able to do 128 locations so whatever. In my experience with seeing other children in the same pre-school even though they are projected to do that they may fall and then they end up with this device that much to complicated and does not meet their needs. So you kinda go on a device hoping that's gonna meet you child's need because of the fact of the cost involved.

ND What things about the AAC device that were important to you that were not considered by professionals?

Well I think that you know high price 20/20 now that you've been involved for two or three years um I would have asked about the portability of it and um the icon sequence, the predictor thing whatever that's really important. There are things about the machine that are important now that I know that I didn't know back then you know that wasn't thought about.

I would like to know what all was available you know at one time so you could make a good decision.

That's what I was saying earlier, I mean I would love for there to be a place where place for parents to go and let everybody come and demonstrate their products and then make a choice. I think that's the only fair way for parents to make a decision cause obviously we're not professionals. We don't know what's out there. What we have I'm very pleased with and I think that's probably what I would have chosen, but I didn't really have any exposure to much you know.

It's almost like it's the size and I agree with the portability. It's ridiculous and I don't know how they could change that, but it's almost like they really need to be a little bit versatile where with the Liberator for example your using icon sequencing, where with the system 2000 I believe um you have a computer printout where your looking at different pages. It's almost like if you had a device that kinda combined those so that you could use them, but then again you'd probably get a device that's so big that you'd have to have a luggage cart to carry it. But I learned too that more it's part of the country that your in on what devices are your exposed to. We went to a conference in Birmingham and I was surprised at all the other and totally different and I'm like Bonnie I'm real pleased with what we have. Marcie does real well with it, but I was you know real surprised that there are just a multitude of different things that are available and of course then you get into insurance. Some insurance companies don't see a certain device as an AAC and there's just not a whole lot of consistency.
ND What should the roles of professionals be when trying to work with you in trying to get your child's device?

I think that you know parents are at the mercy of the professionals. Roles of the professional that I've been to that you know that's who informs you about what's out there. So obviously professionals need to be ??learned around??. They need to be fair to all the different companies and know that again just the exposure to all the different products are the best. I'm pleased with what I have, but I really don't know what's out there.

I would say that they should be more parent friendly. Using words and definitions that are speech professional so you can understand and don't use abbreviations. That's enough to just to throw anybody off.

We've probably had a lot of recommendations from our therapist. You know they assisted us toward the ?proceed? that presented the product.

We had a lot of confidence in her and um so w

ND Well if you could tell professionals cause this is hopefully something training professionals. Professionals today work with families in trying to AAC augmentative and alternative communication devices for children what would you say?

I think we've pretty much covered that. I think the exposure to all the products. I think having the sales reps or somebody in who knows about the different products. I think using vocabulary that is parent friendly um seeing the devices, seeing them demonstrated and I think that's important. I think that should kinda cover it.

Being sensitive to what the parent's expectation is for that child.

And I think in fairness to the professional and also June has mentioned this you know it is just such a terrible worry to parent about the cost of it and you feel like you've got to get a device that's gonna carry your child 10 years and you know next year there is gonna be something better. So there's a fine line balance between getting what the kid needs right now and what he can use in the immediate future and realizing that this is gonna have to, this may have to carry him through high school. You know so the cost is just a terrible burden.

Plus the child itself, each child is different. So they have to have a little knowledge about the child in order to make a recommendation which would be best for it.

ND How if at all are the values and beliefs of professionals different from yours?

The professional that I have come in contact with have been very similar you know I haven't noticed any big difference. What I'm very pleased about is that professional that I've come in contact with which I would expect, I mean I expect it, but yet I very pleased is the respect and dignity that they give to my child and um how they treat him.

Is there any experiences?

I don't think that we've experienced any that would affect like the decision making.

No, I think the one thing that professionals need to understand is they work with children with disabilities all the time. We have one. We never had a child with a disability before. It was a whole new world and you don't even know when or if they are going to speak and if they're going to be able to use sign. It is completely, we have no background whatsoever. We have to rely on the professional and um just go with what we can find out.

ND Is there anything about the subject that you want to say?

Well our first device it broke down two or three times and had to send it in and it took quite a while to get it fixed. So your child is without it for a long time, but that wasn't a consideration when we were looking at purchasing one.

We very fortunate that Marcie was in an early intervention program that had technology, cause she started on technology before she was a year old and ah by the time she was two she had her first device. She'd had loaners up until then. So that's all she's every done is learn on devices, where some kids are coming in later in life and we're just real thankful. I think that as to her, her experience and her um speed with it and her um

acceptance of the device

exactly, yeah

That helped us assist us in purchasing it. She had been around it for quite a bit.

I don't know if this is the time to bring this up, but something that I think is important ah for speech therapists because if I have been exposed to different therapists um you know some speech therapist aren't interested in augmentative device and that's wonderful. That's fine and others are very interested in that and I think from their professional point of view that they should go ahead and you know say this is something that I'm really interested in. This is something that I really want to do. This is something that I will work with your child with or if they're not they should set aside and say this is not something that I feel comfortable with, that I like and um recommend finding a different therapist. I think sometimes children are just thrown into a situation where you know your thrown into with a situation where the therapist who's not happy with that device. Who's not comfortable using it and it's not a very productive time obviously and there's nothing bad about the therapist. It's just that's not their particular expertise or interest, but it is bad when that therapist continues to work with a child and there's nothing, you know no productive time.

ND Any other concerns?

I think that ??name of device?? is wonderful. I think it's really such a, I'm so glad that Taylor's done it now when they are so many wonderful things in technology that can help him, but it's a real challenge to get a child, even a child that is cognitively okay to progress from just hitting some wrote memory stuff you know and then really expressing himself. That's our goal and I think that we will achieve that goal, but it's a challenge.

ND Anything else?

Is that the end?

Focus Group with Vietnamese Individuals

April 18, 1996

Mary Blake Huer, Ph.D., C.C.C., Moderator
California State University-Fullerton

Summary Background Information

Type of Group: Vietnamese Focus Group; conducted by Dr. Mary Blake Huer, California State University-Fullerton

Where Conducted: California State University-Fullerton Dean's conference room

Number of Persons Present and Roles: Dr. **Hue Thi Pham**, a counselor at Art's Coast College, and mother of a five-year-old daughter with Down syndrome; **Christine Huynh**, mother of an 18-year-old child who is deaf and unable to speak; **Dr. An Le.**, Senior Service Regional Coordinator for Orange County, CA who has a physical disability; **The-Luyen Chu**, father of a visually impaired child

Logistical Issues: Brief demographic questionnaires were used as they did not relate to AAC. This group of leaders in the Vietnamese community were selected as they know about disability issues. They deal with and are families with disabilities in the USA. They have no experience with AAC. They talked about disability from their perspectives and their countries' perspectives. Focus Group staff had to make special arrangements late at night for scheduling after work hours. They had a large reception with catered food, tea, etc. with leadership of community. Approximately 25 persons attended the reception then we moved to a private room for the videotaping. The reception lasted about one hour where participants talked and relaxed and met each other.

Modifications Required in Protocol: Focus Group staff used only that portion of the questionnaire for consent, demographics, and instructions about our task. Staff allowed participants tell their stories about their children and asked questions about their feelings as it seemed appropriate.

Synthesis Statements

1. These parents really believe in and push their children to succeed.
2. Support groups are very important to them.

3. Special effort is needed for outreach-radio newspaper.

4. Cultural linkage is important.
    - Try to use liaison
    - Uncomfortable talking with professional if there is language barriers

5. In own country-Vietnam
    - Disability perceived very negative
    - Children kept at home
    - Families protect children

6. Families value education
    - Recognize importance of AAC/devices
    - Often unaware of devices

7. Technology enhances self-esteem

8. Vietnamese respect professionals
    - See as authority but may not follow-through on all recommendations

9. Some families prefer alternative medical approaches
    - Vacillate between Eastern & Western
    - Children must make choices between conflicting values

Transcript

HTP Good evening, My name Hue Thi Pkam. I'm a counselor right now at Art's Coast college. I'm a mother of a five years old daughter with down syndrome. I was pregnant her that was my third pregnancy. I had a son and a daughter and my children are so wonderful so my husband said that helped him more. So we drive over to ?thurkman?. So when Andrea was born I has no idea that I will have a down syndrome child cause my pregnancy was beautiful. I work until the very last day and ah even my boss said Hue it looks like the time has come and if you need to go to the hospital tonight a security will be able to take you. He was jokingly telling me that and sure enough I came home and at midnight my husband took me to the hospital so my daughter was born. She was born about 2 o'clock and so was all right. She came up to my room. 6 o'clock the next morning, the pediatrician, the doctor came up and knocked on my door. HE asked me how I was doing? I said I doing fine. He said I have some very serious news I need to discuss with you. So I sat up and he said there's a very strong probability that your daughter has down syndrome. So I said how to you know and he asked me do you understand what down syndrome means and I studied psychology, I studied so I knew exactly what down syndrome mean and so I said yes I understand. So he said um yeah so there's very strong probability that your daughter was born with down syndrome. I said how you know? He said well because by her physical appearance. Her eyes, her nose, her ears, her tongue was long, her eyes you know just not like the normal not like the other child and you know her the little finger was very small. So he pointed out all of those things and said doctor we oriental and we have all of those signs. I have that sign too. He said right now, I don't know for sure but I already sent for the blood test and then he left. He gave me some paper with my daughters' name on it and with it signed saying probability, probable down syndrome and then he left. Then I was alone so that was very, very, very, very bad moment of my life. I feel very guilty. I feel very sad. I feel like my world had ended right there so I called my husband. My husband was staying with me and then when everything was fine he went home to stay with other children. So I call my husband and I say come to the hospital right away because something is wrong with the baby. So he said what? I said I'm not sure but just go ahead and come. So he came, by the time he came to the hospital they had already took my daughter up to my room and laid her right next to me. So I told my husband that and at that time I think in his mind and I think also in my mind down syndrome that means mentally retarded. That's very clearly appear into our mind and uh my husband and my mind. So my husband took a look at my daughter and he looked out the window and he said I feel sorry for her life. So at that moment I feel like now it is my responsibility to take care of her. She was the special gift that we need to ? rushingly? take of because her life will depend on my life. At that moment I feel strong I feel very strong I feel like the acceptance is not, but deep in my heart I feel very, very sad. I told my husband maybe that was wrong and I still have to hope that he was really wrong and so a few day, then the same day a nurse came up and a social worker came up and they start talking to us about how to take care of her and different programs that they. I stay in the hospital a few days and then we went home, a week later we took the baby home and I gave, keep looking at her. In the hospital I walk around the hospital. I look at the nursery, I look at every single feature of the baby. I look at their eyes. I look at their nose. They just look the same like my child. My child can not be any different from these baby. They look the same, so three weeks later, the doctor called and he said yes, the test have proved that your child has down syndrome. So at that moment, there's no other hope but you move on and do what we can do to take care of her. Ever since she was about four months or even two months, I start enroll her in the infant stimulus program. Start her right away. I was able to make the arrangement at my work that I took her to the group work, took her back to my office. I have a little play pin right next to the chair in my office. So I was able to keep her for a couple of hours Monday morning until my husband came and take her home. So I never missed any appointment either to take the her to the doctor or go to the training or anything. And with down syndrome children, down syndrome child there are so much that you have to do other wise you know a baby will not respond so you have to do a lot of different things to stimulate. The infant stimulus program, even to feed the baby, to make the baby make the eyes movement, the muscle and everything. Every single thing, so we work with her very closely with nurses, with a physical therapy and the great thing was going to the group work with other parents who also have down syndrome. It is so wonderful because you go there and you are able to share with other parents what they have to go through. They will, people ask me how did this happen. I don't know how it happen, it just happened how can I explain it and may be people ask well how old were you and I told them my age, but then why so many other woman so much younger than me, much, much, much younger than me and they have the first child and she also happen to have down syndrome. So there's nothing that we could explain. Now my daughter is 12 years old and she's the most lovable child. She's wonderful. We put a lot of work with her, but she's just a joy to have around. She remind me of how precious life is, quite simple. One day I was sitting with her for the bus to come and the bus was late and I was late for work. I keep looking you know back and forth on the street. 1 you know what she told me, mommy go make a phone call. She was six years old and she remind me that I didn't event think go make a phone call to find out. So I of course was gonna go make a phone call at my work and tell them that I would be late and then after that I feel fine. But she was the one to tell me to do that. The important thing is, it's very difficult to accept, but at the moment you accept that responsibility, then you be doing all right and you know feeling shame, feeling guilty, yeah it was there. It was there because you will be looking at other children. You will be looking at the children that was born the same time she was born and you will compare her and you will compare her with other brother and sister, but you'll think that she's very special. So we work with her. She's now attending Growler Elementary school in a special class, but she's able to speak, speech therapy has been helping us so much. She go to speech twice a week and one day she said mommy speech therapy told me that I have to speak slowly and loudly so other people can understand me. So that is really, cause she could speak, but then maybe I heard her all the time, I may be able to understand her, but other people may not, but there is the way she learned so when she grow up or when she go somewhere by herself, she was able to tell me what she done. So it ah, it's different, it's difficult, but helping her is a joy.

MH Can you speak a little bit about the professionals that you worked with? Your perception of them at the birth or throughout?

HTP Yes, at the birth, she was born at the Woman Hospital in Houston, Texas. So the social worker and also the nurses are very, very, sensitive about my situation. The social worker even came to my house about three times to explain to me what program that they had, either privately or in the group. So they was very sensitive and they was very good about that and then the doctor and the nurse also advising us as a parent to enroll for counseling and they ask a different which I don't think that relate to me, but as far as how did it happen. I don't have the answer, I just accept as the way it happened, so professionally I liked to gather a lot of help and when we moved to California it was when Andrea was almost three years old. So as soon, as soon as I came to California I look into early child education program and one of the first in the program at the college mentioned the Regional Center at you know where Mr. Dr. Le was working so I make the connection right away. So we are soon settled down in southern California I took her to the Irvine Children's Center and we started there. They have intensive, they said that because of her delay, development in speaking especially, but they advise me to take sign language so I can communicate with her by sign language. So I took sign language. I start doing that and we found even that she could speak a little bit, maybe some sounds, but when I cam to California the Children's Center, the speech therapy said don't use the sign language as a with her. With the verbal language, here's the difference because we are bilingual. We speak Vietnamese language at home with other children and the speech therapist at that time did say let's just speak one language with her so she won't be confused because when she come into the group, when she play with other children they use English language and so they did tell me that because with her delay development and if you speak both languages like that it may be confusing so we decided for her sake that we speak more English at home for her. Now she could understand Vietnamese very well, she speak a little bit, but anything that I spoke to her in Vietnamese language she understand perfectly, so she could understand both languages, but speaking she's speaking more English.

MH At her birth with you brought her home, what was the reaction to like neighbors, friends, other family members?

HTP I didn't talk about it, I because she looked normal. Just by, for the look, if people didn't pay attention, she didn't really look, but I didn't really tell many people you know what happened to her what kind of child that we have. You know only I feel like only people who are able to understand I will share. I talk with the people are work. I called my boss right away and so they was very understanding and came to the hospital to see me and all of that so the people at work, the professional people that I know. I share with them, but my neighbors so far I didn't really talk much to them about it. That is some of the thing that happen to many of the Vietnamese family. I feel like many times the tendency to hide it, now I provide or I follow all of the advises from other people to give her help right away because I know that she needs it but for many Vietnamese parents now some that I know move away after the baby was born, don't communicate with other relatives and then even send a child to like a infant stimulus program or anything. I wrote some article in a Vietnamese magazine and people read and called me and asked me about that and I told them that yes that is my true story. Then someone said that I also have a child like that but now even after six months I don't want her to have help and I said oh please get some help for her. So, many times if you do not help those children right in the beginning, you know there's a lot of chance that the children will get delay, and delay, and delay and there's so much that we can do for down syndrome children right now.

MH I think it become difficult for professionals then if they are available to even offer services if the sense is to not tell anyone.

HTP right

MH I think that's where it's hard. It's kinda interesting

HTP Maybe, probably that's a lead. You have a lot of experience working with the parents who having the children who's born with

Generally speaking, I think professional Vietnamese professional have a hard time to accept that their child have a disability, especially mental retardation or speech delay. I encounter a few families both parent are physicians or lawyers that have a children that you know with significant speech delay but also behavior problems also. So basically later on they you know they say ??dinus?? of a jar is autism. I think that the parent have hard time. Each time to talk to them they present me a different way. I know that they are in denial because some of them say straightway like that. If I'm a physician or with both physician why we have a gene like this. So it denial, denial, denial all of the time like that. So I see people you know who are not professional who have children with disability, they, they're not overreacting like that you know, but that very general um perception of me the work with these family.

MH Thank you for that story. I think we'll just move around and take turns.

CH My situation is different from hers. My son is deaf and mute. So we are communicating, with sign language, I make him sign language at home nothing else except I make him sign language. He was born deaf but I didn't know until he got 11 months old when we clapped the hand and he didn't turn right. So at that time we knew that he's deaf and by the time after 1975, we send him to school, a specific school for deaf people and unfortunately we are related to the Gordmans so all the citizens who are not related to the Gordmans we are not allowed, we don't have any right to ask them to that school back in our country. So I feel so sad because we have a visible child and he can not attend any school. It's the only school in our country that I think so. Isn't it? In Litvil?

Litvil

CH It's the only one school for the whole country and my son can not attend it and few years later my husband passed away. I feel exhausted. I feel depressed at all the things, trapped down I feel like she said the end of the world. By myself, I grown up my kids and I said that well maybe it's, as our culture when we have a child visible I said maybe I did something wrong as a ??pastoral government?? it's a punishment from god. So I accept that and until I left our country to come over here and one of my friend introduced us to a school in LA for the school has a special education for deaf people. So he attend in the school but as you know deaf people can not express their impression so he's restless, he's nervous, angry all the time. It's very hard for me to deal with him. He throw away everything that he got. He didn't listen to us. He did whatever he wants. He didn't listen to anybody cause he's nervous and the time flies. He grow ups and now he's a wonderful kid. Now he's 18 years old.

MH 18

CH Yeah, now

he drive

CH I'm very happy because he is an athlete in the football team, attended a ?rich? high school. He's talk six foot and one

Wow

CH Six foot and one

That's very tall

CH Oh yeah for our people, (laughs)

for anyone (group laugh)

CH He has a very happy life with friends. Now he can drive and he's the only one muscle at home. So anything at home that woman can not do he does. So he feel very proud of himself too. And every time that I need help to go to the supermarket or do some ?shopping? He's the one who drive me. I say mommy tiered and he say okay let me drive. He's wonderful. Now he ? ? and he now how hard I have been deal with him since he was a child. So he tried to get better you know. It's not perfectly but I see that he improve a lot.

MH So was it gradual that he changed or was there something that made him change his behavior or his

CH I think that because over here he met friends. They are in the same situation. They are deaf like him, so they look very quiet, but it's very quiet at home when he has friend you know because they come in and they get sign language. So even he has a lot of friends at home it's very quiet. It's very nice,

wonderful

CH So I'm

I wish I had that

CH Even for us only two or three people make noises

I have headache

CH For them it's a whole special world for them. They laugh, they play together, but no noises.

MH Was the sign that learned um

CH from the school?

NH yeah, the same as he learned when he was younger? Did he have to learn new signs?

CH No, because since he grow up, our country didn't go to school.

MH Oh, and did you sign of gesture with him at home or

CH Everybody at home signed. We went to school and we learned sign language.

No she means during the time in Vietnam.

Oh, how old was he when he came to the school?
CH Seven years old

That a long yeah

MH So from birth to seven how did you communicate

CH Just the normal thing like eat, you do a sign for we had out our own sign.

International

MH How many signs did you have? Do you know?

CH We create anew one everyday. We make something new.

MH That would be interesting to see what you created and made up. Those are idiosyncratic signs.

CH Like out own sign, like when mom dies it's meant like that. When mom die so we have our own sign.

MH So then you started to learn sign here when he was seven

CH yeah

MH Has he been at the same school?

CH He was, we were in Los Angeles and we moved to Orange County and he was
?? ?? in ?Hutchville? High School, but before that he was at University Middle School, but in on ?vine.? Now he's going to West College.

They have a good program for hearing impaired

Wonderful

CH Now he can fix a little bit of his own car because he's in a class so he's learning so he can fix his own car, even if he gets in trouble with a car he can fix it by himself. Sometimes he help with my car too.

MH That's amazing, they signs, that's interesting so

So it's very important there

CH You because of that at my work I earn extra money can I know sign language because elderly people the loss of hearing so they sign too. That's why every time that we have a patient, I'm a nurse at the hospital, every time that we get a patient they sign, they call me so I have extra money for I got extra for the sign language.

MH Wow

Bilingual

MH How about his, again your neighbors, his peers does everyone that he interacts with sign? What happens if people don't sign? How do they communicate?

CH They create their own too.

MH So they, their doing, they make up things and they kinda understand it

CH But he has his own group of deaf and mute people that went together to the church. They went together to Disney Land and sometimes at those places they have a special day for that people. Yeah, like at Disney Land sometime, I think once a year or twice a year they have a special day for that, so all the deaf. I think the whole country pop over there from all the states too. Yeah

MH So socially, he's pretty much with the deaf community, interesting.

CH That's why I talk to Dr. Le last time. I said that I hope that we can create a center for deaf people. They can come there and communicate together because they will feel boring if they communicate with us. We can not keep them long if we don't have people who communicate with him with the sign language.

MH What does he do for the telephone?

CH He has the TDD. That device and it's very helpful for him

So in the send, in her son case I think that the reason he is more happy here compared to what we like in Vietnam because at least they have their own community that can interact, they understand. They're living, basically they're not there if there not there. No just the deaf but everyone who are disability there because there is no activities for them. That they can participate and enjoy or share, that basically

MH I'd like to ask a question because part of what of what I'm interested in, is any kind of technology, cause that's, if you go to the most severe end of communication, there is no speech at all then there's a machine that talks. So the telecommunication device that he uses for the telephone...

CH yes
MH um, how did he react to that initially, or how did you react and the family in the community to that piece of technology to allow

CH I don't think that many people in out community know that we have that kind of device for deaf people, not many.

MH So when they

But when they know they are very exciting about that, they love it you know.

CH Most of, because of our culture so when people they have a disable kid they want to keep that kid at home. They don't want to take them out of the house. They kind of shy and they don't want to let anybody else know their situation that they have a kid who is disabled. That's why the kid sometimes, they lost of lot of rights and they can't ?live up ?more than what they see at some because when you go out you see this so your mind, your branding love. If you stay home all of the time you don't see anything.

Social skills very limited.

MH So would it be correct to say then that in the Vietnamese culture the families would totally, their preference would be to totally to provide for a child who is disabled in their home. That would be a preference where as in another culture, their preference may be to seek as much help. So I'm trying to

But we have to make a the clear distinction about that. When we talking about Vietnamese culture or tradition here, we mean in Vietnam. But you know after many years working with Vietnamese with disabled children I think as long as they understand the benefit you know we'll have the children to develop either socially, educationally or you know basically anything they are very eager to cooperate with you. So we have to make it clear here, so we don't misunderstand that the Vietnamese family live in this country are not open to ah getting services or speech therapy or physical therapy or other educational services, special education services here. So, because we in a transition here. The issue here is not many like she said, not many Vietnamese family know that people can communicate through the telephone ah especially for the deaf people or they don't know that some children totally nom-verbal can communicate through what they call communicative devices or something. Once they know that, they are very receptive

CH Most of deaf people, Vietnamese people they don't know that they can drive. My son he tries

Right
MH interesting

CH Because it's that they can't hear how come they can drive. If somebody honks they can's hear and if the police calls them they can not they don't now neither.

Group um huh

So that afraid of everything. They say oh I'm deaf, I don't go on the street. I can't hear, but they are wrong. The things that I want to bring up for deaf people community is knows deaf people it's not the end. They can drive. They can like my son, he's in athletics, a football team. And he tries and he do everything. He's physical is perfect. He's tall. He's strong. He eats like 6 bowls of noodles at a time. I can't tell you. He's, his physical is perfect, except he can't hear.

And she exactly right, that is the key, not only with label, but with the physical. That's why I created the support group. Now, it's not in Vietnam anymore. Why did it be that way in Vietnam, because there were no services for no matter what disability you have. You are deaf and it's no war going on, many years you know, therefore we she very eager to have support group for the deaf community. Now is the key, you just open to them, very easy. Hey, I can do it, you know. I'm deaf, I can do it we're not you and here is the way to do it. You see? That's why she and I care very eager to do that. That's why I created support group. Very easier, you know when they come, they ask any questions, very informal, and they say in Vietnam like me- you are useless. You are not going to be anything you know, but over here it's not Vietnam anymore, so a person with a disability like me- I went through that in Vietnam with 21 years like that. When I came here, I make it a ?judgment? to this country you now to know the system here. I work very hard. I become functional, like everyone else here you know They say what are you sure? More amazingly about career wise, but family it's impossible. You have wife? You have two children? Yes, I do and I can do very well, you know. And not just you bragging about what you doing, but someone like me I have a dream that, no no I want my friend, other friend, Vietnam student who have disability it's nothing you know. You can do whatever you want and I even bring one of the supervisors. She's American, she has CP since she was born. She is the supervisor now and when she compete with the four position they eliminate all the supervisor. She is the one who got one of the four among thirty of them. I brought her to the support group. I said here, see it you know. That is the way and many people with disability, they an do a lot of things. Special physical disability, like that or you now have polio like me, very powerful. You can do it and you know that's how we in here, you did it and you say you watch over like you can do it to and enjoy life too. No shame here, no anything if you can live you know like everybody else and you did writing. You do writing and you work hard, nothing to be ashamed for. Forget about Vietnamese culture you know

So is that the question? Adjustment, how you can adjust to the life in America? You see but for the old people they very hard the edge do horrible more hard to adjust to American life and for us. For old people, assertive sometimes means a ????in American if your own and not assertive you can not get what you want. But social, sometimes I many times I tell a friend you don't ask for a favor you just ask for your right. People have to give to these children you have to turn this you don't make it into, but you see with many people with cultural, most of these people, they don't like to listen, they except it, not demanding. So

because they think that whatever they ask- do them a favor it's not to demand their right, but to do them a favor. That's why we had to ?lecture? and let them know it's not you asking somebody to do you a favor, but your asking for your rights.

?Do you succeed because you are just well?

That why Luyen Chu is conducting 11 workshop right now. You see the key is education. New things here, nobody know. They still live under cultural you know wall that you no good, you no good and the more they come here they know a lot of things about that. No they don't why? because she said it, they keep it inside. They don't' know you know. They don't know.

So I ask ah Christian to present to speak on adjustment to American life or perhaps you. We need that adjustment

CH It's so amazing too because my son he took me sometime to his deaf club that they dance. They have party life us. He introduce me his girlfriend, very beautiful girl and he said here's my girlfriend. It's very amazing of that because they can not hear the voice, but they can hear the sound. So when you play the music boom, boom, boom, they feel it. They dance.

And sometimes the sense it too. yeah, yeah

Yeah, but in Vietnamese culture, I mean traditionally and she mentioned a little bit but I did the whole my research on my doctorate degree subject on the perception, we don't have many material on Vietnamese, but we do have on Asian in general and basically we Chinese people and I found a lot of things that confirm what she said to. There are four explanation with disability no matter, mental disability or physical disability. Disability is disability and one of the most you know common explanations for having disability is god's punishment. I did something wrong just Vietnamese, I've found in American materials here also way back before Kennedy time people believed the same thing. Many handicap people who become famous professional. One lady she a clinical psychologist in San Diego. She wrote a lot of book about disability and they believe the same thing you know many years before that segregated people with disability here, that's why we have a lot of institutions outside of the society, mainstream society and then after

Kennedy. President Kennedy had a sister who had mental retardation. Remember that? That's why special Olympics was blooming, but basically again, but that's very powerful. God punished me, I did something wrong and then what my mother when I was a few years old. I had a high fever and they say that I have polio virus so I was paralyzed after 24 hours you know. Then you cripple for your, so she keep me, like she said in the house not because she intended they don't want their children to learn or anything, but I don't want my son, my daughter is ridiculed or make fun of my others.

Protecting the child

Yeah, protecting he has enough already. I don't want to make him be more miserable and he going to kill himself or herself. See, so you got to see two sides like that. See speak for the parents perspective, but I speak from the child with disability perspective. May years I was crippled, nobody wanted to talk to me you know you are......they look down upon you um so so I there's a lot of things going on high up there with their attitude and after many year I have been conditioned by that I become to think that I'm no good. No good, I'm not worthy to talk to a girl. You know who would want to talk to a cripple guy. He's no good you know. That's what society says. So that hurt, that hurt badly. It's hurt my mother badly too. I remember many years there were times ?????I the floor and she said I your bang my house I go to war.????? I say I want to go to school. you know why not? why not go to school, I'm smart enough I can learn and she said oh but they will make fun of you. I don't think you survive. Your not going to survive guy, you know. I don't want that rather you stay home and mommy will do whatever you ask to you know, but that's very hard for the mother to endure and she said later on she said to me, she say son you can do anything in life you want to. What a foresee, you know. What a vision my mother had and that really, that really come to me when I came to American. Still 21, I consider young to learn and you know and I came in and lived with an American family and I see they treat me well, like a person. God, like what my mother said, wonderful and then technology services, you know many things come at the same time to make your dream come true, but I told my group you have to work to death. You still have a hard time to get a job, but that's nothing for you, you have a double challenge. American with disability said that they have a hell of a time. It's not over yet. Your barrier is still there. Now you are disabled, but you are Vietnamese also. So you have a hard time, so don't say that over here because you talk to them the way to do it, but then you also discuss with them the reality you have to face. You have to work twice as harder than other people but the girl she in second year of college, she's in that article. She have severe CP, but know she A in everything. I don't think that without my support group and she's a pager of my support group. I want to be a child psychologist and I think she's gonna make it, but they need support. They need constant support if you doubt anytime

MH Are there groups?

What is good is Vietnamese is sure idea support from the family and from parent you see even if your child is grown up 30, 20, 30 whatever age if you still need the parent, the parent is always behind you and will you. From my own experience, my so who is legally blind. Back in Vietnam he had to quit after junior high school, but when he come here we push him to learn and know he come I just thank for computer. Back in Vietnam, we can not reach ???it until 21???, but here we had to show him that he had a future, to know he had to push him so parent play very important role in life.

group agreement

And you daughter have a seizure

My daughter has epilepsy. She no longer has to be at the Coast College. She will graduate by the end of this year. She goes with psychology.

MH You said

I have also a step son who have Down's Syndrome, but you see here with special education he kept improvement, about, he can know write his address, his name, so on he learns better, but back in Vietnam like she said

My son when he write show him a switch of a friend or somebody he can look at the map and get there by himself.

So he has a lot of opportunity , but he has to know how to use it and you have to like a push the children.

MH Do you think, do you know that there are support groups in other states as well as in California that are similar to yours? Have you linked with them or do you know or have any idea what the other communities

The reason we created here after many years we need one for many years for the parent with disabled children Vietnamese parent with disabled children and I did for Vietnamese young adult with disability because we have a lot of Vietnamese living here, but initially when we present something like that we both. We have hundred, hundred organization but non for handicapped people, because they don't want to deal with it. For the majority of people, I don't want to deal with it. This is shameful stuff. This is negative. This is no good you know. There still out there that's why I, after I started working and you know having something to do with the community. I take every opportunity to be out there and inform them about it because they begin to believe you, you know if you are disabled and you can't do anything, you can not support yourself, you don't have family. What are you talking about? Are you dreaming? No, so it's powerful for, we Vietnamese culture for a person with a disability, that they become something and they an be independent with their life and they can be like everyone else in the community. And then you can talk. They take seriously, so it's very recent, after 21 years. Nobody going to do anything about that, so I really encourage her to, because we have plenty of enough of like Vietnamese people mute and that to start support group, you know? When I started, I prepare very well, and I was amazing that about 48 people show up at the first meeting. 48 and now we do thing together sometimes. That show, like last time we have almost a 100 people. It's amazing, but I asked that in my dissertation there are 10, 000 Vietnamese in this area that are disabled.

You can not reach to everyone

But my major agency and department have served about over a 1,000 only. You can see how still the theory of hiding and keeping their places, but other regions like Dole people with mental retardation and when we place them in the program or workshop parent don't want it.

That's why I look at Vietnamese people and seeing who well my daughter has been doing in school. They were amazed because they have many of my friends know other Vietnamese parent who have children with down's syndrome and either they was born in Vietnam and they came over and then they have not done anything to them and now they don't want to take any services for those children either. So there are many other Vietnamese children who have Down's Syndrome or maybe young adult that have not been reaching out by any help and that very sad because like you know Dr. Le mentioned earlier for like a child who born with like Down's Syndrome you know long time ago they put them in an institution. They didn't do anything with them. They given them away and the doctor would say don't worry about taking her home. You know so that was

Even to suggesting to put her into

To put her into the institution and now there just so much you can do for a child like that.

MH What are you doing to try to I mean what are your plans to try and reach the other 9,000 that you project that are in this area. What kinds of strategies are you using?

I question of outreach is very important. We know that there are thousands of people that need services, but how to reach out to them, so we start with the many newspaper and radio. I think that you just know to send for gradual

Lately you have some radio announcements about this organization.

So you must do it at different times and forget and miss that radio is the best way
MH Radio

Before I came on TV Dr. Pham you know come on many times to share her story you have to do a lot of things, but my goal is not only to go and talk to the populations who have disability, but I try to reach out to the Vietnamese community in general also. You see and the good things that we Sigon, Little Saigon, the jockey is the Vietnamese guy, he have polio severe than me. He is single. He composer and he did a lot of so activities that related with ??refugee, refugee gain????? So he internationally know and he's on TV everyday. He's the jockey of the radio. So we have some good image that to build up.

You see the system here is very complex and people need a starting point and I think the parent group is good starting point. So had to let parent know that you have a starting point, come to us and we'll guide you.

And we starting to give out some grant and like Luyen Chu they had that grant to him. What he do, he trying to, he work very hard and it turn out very successful. I saw about 40 people, 60 people. You start with something that you have and you hopefully, they we will disseminate that information as time go bye. you know, I got called now when I went on TV and radio and when support group and when I have a newspaper, people call me from LA, from lots of time I have a lot of call Glendale, Burbank, they say you know I came here 5 year, but I didn't know that we can do something for my son or my daughter. What can I do now? So you

I have a call from San Francisco for

Right so you have to prepare to respond

I'm wondering with very specialized training like we have, even the speech pathologist there are very specialized areas and our work here, our center and the students who are training offers one of those very specialized areas for people who are in a wheelchair and are very involved. If we wanted to reach to Vietnamese community to just say these are services we offer. If you have a child that might have this need how would we reach out and do that? What would you suggest to us as far as a strategy to say to identify and offer services if people wanted?

That's very easy now. No five years ago we didn't have the media you know. Now it's easy you just write up the summary about what you want to do, what you offer, what your services are and then we translate it into Vietnamese. Now it's on the radio. It cost you ten dollars or twenty dollars for announcement. You start it from there and hopefully people will call in. The last one I did my support group, what did we do in the support group and the day after that 26 calls in my mailbox you know, so the problem is that if you open something and you can not respond to that then you out. People don't trust you anymore, you know. So when I started the support group and many, one of my supervisors at Rancho San Francisco College he said I', crazy, why you give them you home phone number. 11 o'clock pm some lady called and said she depressed to death. I say what you have? What problem do you have? Oh, my foot I have polio and I walk like with unbalanced gait. I said come to Ranchos San Diego College, at that time I was counselor there, meet me and when you see me you will walk all over. I walk with a cane. It hurt me to death with brace. What is your problem? Lady, what is your problem here? I walk with a little gait, okay , but I never when I came here 5 years I never go out by door. I feel so thankful, but that's they're world. They're reality. They feel shameful. You might laugh at it. You might think it sounds ridiculous like me, but I didn't dare to that. I just say you know I understand, but you now I walk with a cane and people on wheelchairs you know and they over came this and your situation, it's not that bad you know. Try come first and see it and if you think that you still be shameful, you still be fearful then but get yourself a chance to come you know. Something that they just don't know. They don't know, so now my support group I have the letter and every Monday sent to me the letter and they talking about their problem. What they do to get meaning in their life, you know. I put it on letter and everyone can read it you know. That's one very therapeutic. That's why I got my degree in psychology. Basically that it.

MH Do you think that um, I 'd like to hear speak any of your little bit about how comfortable persons would feel if they would go to a service provider like myself for example who's not Vietnamese. Does that present problems? Do people seek out expertise and information or do they feel comfortable? Can you speak a little bit about that as an issue?

If they disabled or the parent with disability um when they go to the professional, but their not Vietnamese how they feel about that?

They don't feel comfortable because of the language they can not express what they want or what are their impressions because they can not express with you do to the difficulty of language

MH Even if there's

Even more so that part of them, but other part is that I have a lot of Vietnamese who fluent in language you know they young here. They 25 have a job and I still want a Vietnamese worker, so it's more than the language, but the cultural

My son and my daughter who speak well English still want to go with Vietnamese Tradition. They want to have a Vietnamese worker, cause maybe the relationship could

Cause it's easier for them to talk

Related culturally. Is that normal or weird or what
MH No, I think it's very normal. The problem or the concern that I have is that there aren't very many at this time and that's why they are training programs are some important. Persons who are Vietnamese who have the specialized training, now we're trying to recruit students and train them, but there's always this time lag between the time people have training and the time and the needs that are still there and so the next best solution in my opinion is to take someone who maybe isn't Vietnamese, maybe they're Asian, maybe they're Hispanic or maybe they're African American, but they want training and their want to offer that to persons with disabilities whatever the culture may be. So my role as a teacher is to try and figure out how to make people as comfortable as you can when you don't share the same ethnicity. So that's my dilemma here in the training program is to give them skills that are useful to the Vietnamese even if they are not Vietnamese. So that's

Again idealistically speaking you know like when the regional center opened we don't have a Vietnamese worker. This fears Vietnamese consumer or client coming in you now and they might feel little bit uncomfortable at first, but hopefully if someone who do not speak the language and they have an interpreter it would be okay. If someone who speak English and they communicated at first they feel uncomfortable little bit, but so what. Later on they get you except rapport and they can go on and it can be wonderful. So when you ask us we respond in general.

MH yeah, yeah, yeah that's

That's a mean because I see a lot of when I was at the college you know some Vietnamese wanted to come in and see a non-Vietnamese speaking counselor.

So of them will be more comfortable with a non-Vietnamese.

So with the transition here assumed that every Vietnamese will, they might prefer you know but they are not terribly uncomfortable. Like, me I very comfortable with Terri all the time. When she call me I get all excited. I say when, where, what. I didn't even read the letter you know. Now I look back and I say oh, she asked me to go parking and these other I say no I'd say that I didn't read so

I'd like to add something in here as far as professional services they look like 300,000 Vietnamese people here in the Southern California, in this area and career wise it look like more and more Vietnamese are going into engineering, into science, into

business

into engineering, business, all of those areas. Not many people are interested in psychology, education sociology, speech pathology. You can not even find one Vietnamese person who specialize in the area like you are thinking right now.

MH We have one undergraduate student

And also education, no many people are going into education so that would be another area as a community a that as a community we need to many people more aware of it, but as many other careers besides the one that they want to get into to make good money and so on. Really choosing a career, that's something that you like to do. That you enjoy doing, even if you do not make a lot of money. I think that there are many many Vietnamese young students who like to do something that they like, but there is still some advising from the parents that you should not do it and because I can seen, everyday I seen students who are capable of becoming a very good teacher, capable of becoming a very good speech pathologist, but they shy away from it and I say why. Oh my mother told me to take this. Oh my mother told me to become that so they really need to have a lot of encouragement to do what they think it right for them and they also need to have a lot of encouragement to do what they think is right for them and also they need to have a lot of encouragement and training for parents to be able to open to other jobs for the children. That's what we need in the Vietnamese community because other wise we are going to handicap in what we call specialize professional services among ourselves and people are capable of that but not using it.

MH How do you think we could recruit more or have persons be more interested in education or speech pathology?

Well, like before I was in advisory committee, advisory board at California State Long Beach to have a grant what they call bilingual teacher but all specialize in disability and they the one who ??enjoy?? and they go along with the Vietnamese person there and they inform the community and I think you know our 3,000 people some people respond. I saw like five people responded to that grant and become a bilingual teacher.

Make it available. Make it know to the community. Here's a scholarship you know that's say if go to Cal State Fullerton and you specialize in this area tuition free for two year. I'm sure there will be people responding to that.

Dr. Si say that they guarantee for you for two

She has graduate grants where if people who

No, but you said that in this area the shortage of that's

Oh yes

where we want to communicate it

MH Oh yes, tremendous shortage

Your gonna get a job and that's one of the motivations, right now nursing when I a counselor over at Rancho 8 years ago you know part of them was the language problem and part of them they say oh it's hospital only. How can you find job here? and after that a lot of people in the nursing department say that after you end the training you will have a job right away. Now, how many Vietnamese are in program over there. There is a long list. When I left the college just last year, I know 10 of them become RN and now encounter them at public health nursing. How's nursing? Wonderful, Dr. Le, hi now we working with same client here you know. So you do the best you can to inform the community so of them who have a very noble goal. My sister you know has a speech disorder I want to become a speech pathologist to work with this population that's all.

I think back to your questions. I think that if you have the grant, if you have the money, if you can give in the form of the scholarship. You will get people who will respond to that and especially if you inform them about the job out look for the future. The question that a student will come to ask me, Dr. Pham tell me what I should study that when I graduate I will get a job. Now I tell them speech pathologist.

MH Good, good

You know that is the question that they have seeking for.

Another way, another means to encourage this one, but just form a personal commitment like me. I go to different colleges and when they have career planning program, counseling class and invited me in and this class about and most of the student in class are Vietnamese, so they say okay can you come and talk about careers in psychology, counseling and social work? I came and talked and when I came in I said I see about 50 of them I say how many of you planning to major in psychology. NO How many in social work? How many in counseling? I say good bye. I don't have to talk about it. No, no, but kidding and after many times like that, last year two of my Vietnamese interns as Regional Center are Vietnamese and one of them say. The boss ask them how to you get into this area. Oh I heard Dr. An Le talk when he was at Rancho San Diego College and he talk about career in social work. He convince me. That I can have a job after this and I like to work with people, but see they don't know. They don't know and they're afraid about the language when you say that you study psychology. They say what? How would, second language how could you do it? It's very difficult. It here when I come in and say if I can learn and study about it when I come here at 21, then anyone here can learn about it because you are younger than me when you come here any way. So you give them some kind of confidence and they believe you because you did do it. It's very powerful.

MH I want to ask you another question and I apologize for jumping around. My field deals a lot with technology like we mentioned earlier with the telephone. I'd like to hear your perception or opinion on your communities responses to computers or um computers I don't know if you've heard them now that talk and um special switches that you can blow, or sip and puff in or use your eyebrow and the door will close all the kinds of technology. The modems and internet, kinda like to see your community's perception of technology. Just specifically

They love computers. Just two years ago when I read an article and it said I guess a computer is going to become like a TV. Every family will own a computer and really said that could not happen and now in my own home I have two computers, because my daughter needs one and my son needs one because they need it to do their homework. Internet, they have their own internet in Vietnamese language they connected all over the world. So the Vietnamese community are very aware very, perceptive of the computer. So if there's any kind of devices that helping them to communicate and if they know they will use it. They will use it because with the technology they are so much and I think that is why you know that is why many, many Vietnamese people like to study computer. West Minster high school offers the whole class computer training for Vietnamese parents

You know I thought that most of deaf people where very successful in the computer field because they don't need the sound. They just concentrate on the words on screen and

And my son who is legally blind, he enjoys the computer too. They have a special screen that you buy . You buy the talking what he typing

MH Talking keys yeah

And for the telephone device for deaf people it's a kind of computer too. There are words that show up on the screen and the other side the operator reads the screen and talks to the other person.

MH So it sounds like they would embrace all strategies for these that are in wheelchairs that are severely challenged that would, cause some persons are very uncomfortable with technology so that's interesting.

You think that someone come from Vietnam like us, you know especially I'm speaking from myself as a person with disability when I can drive that resolve a lot of problems. Not transportation problems, but it resolved by self esteem problem.

You empowering yourself. Exactly, so you asking about, I can answer to you that I love it you know. It saved me mentally. It saved me

It freed you

It freed me. It make me somebody. People see that you know he can try to walk. Some Vietnamese when I talk to them they say can I take you home. They don't think that I can drive home. I say what? I have to have drive license before I get this job. They don't believe that I can drive. Can you believe that? When I show them my friend who came here at the same time with me who is on wheelchair. He can drive the van, the big van. They say wow, woo, wow and that result of some of my friend mental health problem. You see how powerful, it's not simple like it resolved my transportation, but it's very therapeutic. It make me happy.

It make me happy too because my son, I don't need to pick him up.

I remember, I remember six years ago I had a client. He's Korean. At that time he was in high school when I had him. He very involved, you know his speech, none. Nobody could understand him. It take him two minute to utter a sound. I couldn't understand him. It took him two hours to take a bath. Motorically he's so involved. You know six years later I met him at Rancho College. You know what he did for a living. He doing music transfer tape and he making 15 or 18 dollars an hour. I said you make more money that I do. He's so happy- career and family, even more close that Vietnamese too. God working with Korean family, they thought severe CP and when we said mentally your daughter you know paper work has been done and the team here review and they said your daughter is eligible on the bases of CP. Say what? Cerebral Palsy, what? What does Cerebral Palsy mean? Don't label my children, okay? What was the different? His condition you know many years anyway. See what I'm saying? Unbelievable when your talking about cultural perception and the doctors, Vietnamese doctor and the doctor say um he's autistic and he's also function at the moderate range of mental retardation. They say what? He's autistic that's okay, but not retardation. What are your talking about? You see. they react. That is some sensitivity that I learned over the years. I'm not going to inform them like that. I invite them in, meet with the team and let the CP let the physician inform them and if they have autism let the psychology team inform them of that you know.

MH I want to probe a little more to what you just said. What's the perception of decision makers. For example, some people like to kinda like to collaborate, some think that professionals have all the answers and just listen and follow it blindly. What's the perception, generally in the Vietnamese of professional and their opinions and their advise? What's that relationship specifically?

Some of them, if they trust you they know you are the doctor of seizure disorder when they come to the doctor they take and do it. No question about it.

Straight line down

Yes, straight line down, but you have to establish your creditability there. You know, let's say that my daughter have a seizure disorder and I go to a Neurologist, Dr. Fowler, a very famous guy at Jock. I just sit there and say yes, yes, yes doc, yes doc. When they come to me I ask did your child see Dr. Fowler last month? yes What type medication she's taking. I don't know. How may times? He asked me to give her three times a day. For what? I don't know. I don't know. You will see that type. Blindly follow the instruction of someone they know has an absolute authority.

But then they may go home and they may not practice it and then they get into trouble because they're not really learning through the process. You know how to evaluate what they have learned through. They do not evaluate that and then in the doctors office just because the doctor is an expert in this area they listen to it, but they don't apply that to their son or daughter. So their son or daughter you know in contradict to it you know get worse and worse and

And that depend on the issue because a seizure disorder the issue is the family too because they believe eastern the medicine and now it's the ???blue median?? on both side area that did that. I know some young girl had a seizure disorder. They listen to the eastern medicine, they don't give Phenobarbital or Depacon or other medication. They say that hot, they say that make the children hot. So they go to the eastern medicine and it didn't work very well. It didn't control her seizure very well so that

All of the her medication you now the natural kind of medication which may not be good for everything.

right

MH It's interesting the fields of allied health or medicine in the community, what would be the range of practices I guess, if I could ask it that way? Would they go to doctors only of if they would go to other types of healers or I don't know what the range is?

I think that many of them are still going to MD, but now there are more oriental doctors, um Acupuncture and then just an herbal doctors and many Vietnamese people still feel like that kind of medication is better than western medicine

And sometimes they just try to see which one is working, since they follow. They want to try the oriental, if it doesn't work they try the MD.

MH So they might do the range. I don't know how speech would fit in that range if it would be the more western model or I don't know.

I think it's more western, because it's more specialized training and I think it's more into the scientific kind of research because if you go with what we call the eastern medication or oriental that sometimes you know they may be looking into some myths. So and so that may be some devil. That be submitted because there maybe the devil maybe in that person and it's why they prevent that person and then maybe they will do mysterious kind of healing over that which may not be work. So like a speech pathologist or any listening device or speaking devices or whatever it be more western because that is more scientific with the research with the proof and everything.

But with my family who have children with speech delay. I met the speech pathologist for sure, but I have to push them to go to speech therapy. So the way I present the approach, I go with them is I say this is very educational. This children have to learn to talk you know. School, school, school they love school. So if you identify yourself ask like this you teaching the child to talk. It work better. It work better.

MH So to stress education is a key to

yeah,

right

MH to improved communication

Communication or speech

MH relationship

so many

MH Instead of medicine, education is the key verses allied health.

Right, right and they go back and call your value. Education is highly you know respected. When we go to the professor, we call professor Pham or professor Huer, but we don't call oh hi Terry. No I can not do that. Even now I can not do that either. You know so you have to know. That is the advantage of the person who are bi-culture. I don't play something unethical here, but I know that this will work and that's for the benefit of the child you know and that's okay. God forgive me anyway. So it doesn't matter to Christianity or I am a speech pathologist. They wouldn't call it pathology in Vietnamese. That means you know sickness, like psychopathology wow, wow.

I say back to you we have a saying in Vietnamese. They say that education is second to none. That is the best value. Under the Confucius philosophy we place education very highly beyond any other values. So the parents always encourage children to have a high education and to go to school and so one. So we now need to apply that same principle to anybody who has disability or handicap.

right

We just have to tell the parents you know they have the right to say that education is second to none.

So before we finish it I want to make a clear to both of you so we don't have a misunderstanding here. When we talking about traditional culture it's different, but the Vietnamese community is in transition.

MH Yes

um huh, um huh

You know I'm a very optimistic guy you know. I don't talk, let me give you the metaphor when I'm in this area and that's it you know Vietnamese counseling doesn't work. They don't talk. When someone come to my office they talk like nuts. I can't shut their mouth you know. So forget it. So they say Vietnamese don't tell their feeling in front of people. Wait a minute, over here they know that social support system is no longer there. Then for surviving eastern they reach out. You Vietnamese you understand me, but my college who is not Vietnamese they talk like crazy. They see him every week anyway. So my point here is that you know it can't, we don't generalize things. I work, I have spent many years with especially adult developmentally disabled people Vietnamese people. Initially, they didn't allow their children to go to the program. Are you going to guarantee that she's stays out there like you know no car hitting them. They worry about their safety. What happens especially girl, if she gets pregnant are you going to be responsible for that? Okay, you know, but these are I work, work out perfectly you just tell them the benefit. You tell them the risk, but even for me or for my daughter who not retarded. They wish to be read to, so why not? The people who have a similar um right like she said her son is deaf, but if she not allow him to be out there and to be like other guys you know. Have chance socially to be with someone, then he never be afraid. Right? That's what I work for and after I say to them and I good in Vietnamese standard English. I say well but Mr. Chu you have a right you a parent. That's what I say because I see the benefits there you know. Of course, they go to have risks too you know, but we make a decision. Okay, so Mr. Chu take you daughter at home one week, two week, three week. I can not take her anymore. Can you try to her to go to program? After she go to program on the weekend. Sunday, Saturday she call back and say can I go to the program and Mr. Chu say no, no, no day program on the weekend. And then you give that example to other family. You have to let time to work on it.

The most important thing in the in most oriental families they always want to support their kids, even they grow up 40 years old, 50 years old. It's not like here. As long as your 18 or 21 your independent. You try to earn your life my yourself, but with here the Vietnamese people they don't make their learn that way. So we never know in case of an accident I can die. He can die and our kids can not survive by themselves. And the most important thing that I want to share with Vietnamese people in out community is how to make our kids learn to survive my yourself, by themselves.

When we pass away.

Because we never know. There's like thousand accidents a day in the United States. We never know. I can die anytime. You can die anytime.

That's the excellent point. The excellent point.

Here we don't have the support of the extended family as we have in Vietnam, because in Vietnam you always surrounded by your relatives.

Right

And your grandparents so that extended family has become you know your protection blanket. They're your comfort zones. That we don't have that comfort zones and I think that I've seen a lot of conflict. The children I hear learning to be independent from American school and then when they go home to parents try to protect them. Then they really you know the seeing that being independent of something that's against their authority which I think is totally wrong because a child needs to learn to be able to be independent. In case that the parent like them or they need to learn how to survive.

Because they live here. They not living in Vietnam. So some how you have to confront the issue, but gently you know gently.

It's very difficult and I think those are the ??program?? and I emphasis over and over again. You know that anytime we talk about you know educational system or about parenting program or whatever. That's one of the things that I think that we need to emphasize. So more and more parents be able to understand because otherwise you will put a child into a very conflict state. They don't know what is right to do and what is wrong to do and it's very difficult for the children.

right

There's a big different between the two cultures.

Last week when you went on TV, you talk about a career choice. I think you make a good point and say. She didn't say what is parenting wrong, but she say okay that might be getting conflict if Vietnamese parenting this way and if their children have a talent or ability here and because they want to respect the parent decision they will shy away from their talent. And she pointed out something else. There is no confrontation, direct confrontation and people observe that and hopefully they'll think about that and they can open ah you know more.

MH I want to um kinda play off of what you just said about the perception of children, but go the opposite extreme which we work with here that is the elderly individual family member or the older adult that's in an automobile accident or some kind of head trauma or stroke. In the family what happens to the perception of that older disabled person? Do they shelter them? Is there a whole different strategy that's imposed or what happens in the family of an older person with a disability?

Depending on different situations, but I know one special situation. A very you know a very, very good looking student graduate from UC with a computer science major. One night he came back from work and fell asleep at the wheel and hit another car and then he become completely disabled. He had to, he was in the hospital, unconscious for a while, and did know if he would come back. Then come back it was almost like completely disabled, mentally and physically. He had to learn how to ??draw and ?? like a baby, but he was luck to have the mother who is so lovable and who is also so open. So the mother become the caretaker for him. So the mother has been taking him going in into our class. We have a special program that we have for adapted PE. So he learn how to walk. He learn how to do that. So it really depend on different, but this particular situation I know that the mother has become totally committed 100% caretaker for this young man. And then his brothers and also his sisters are very supportive, very helpful to him. They all make a lot of contribution into his life and eventually with that loving and especially learn how to speak again. He lost his speaking ability totally. So then that end up the worst case that I could see that it happen, but I think that because here in this country when there's a accident or something like that you are in the hospital. When he was in the hospital he was informed by the doctor and by the nurse you know what service are available. So I think they, because it happened that way, I think they pretty much open to the services and I think that otherwise, but here's the services. So what can you do, but accepting it.

Sometimes it depends on the family situation. I knew that the lady that she had a stroke and she partially paralyzed. So she need a caretaker and a friend of mine so she works so she couldn't stay home and take care of her mother she kept in conflict. She wanted to take care of her mother, but she wanted to go to work also. She couldn't do both of them. So she got to place her in a nursing home and she come to visit everyday. So it depend you know, but most of Vietnamese family still want to keep their family at home, but you know at the same time they are so stressful because they can not handle everything at the same time. So it become a issue you know that eventually they couldn't handle it and they end up to place and similar to where I work. A lot of families have children that are so involved, that you have to place, but the mother tell me that mentally I know that mentally can not take care of her well and when I place her I feel guilty, like bad mother and she cry. So there is the you do or your don't. You're no good anyway.

Yeah, you can't make any decisions.

You just go and until you drop you know. So we don't do a lot of things like that. There's no simple solution.

MH Well I think with that we should kinda wind down cause we're talking until we're going to drop here. But it's actually fascinating. I appreciate you coming and sharing your stories and the information and I hope and look forward to the future when we can work more closely together. Um I'm really glad that I met you and we have the training program here and certainly we would like to spread the word that we would like to train and support and finance and recruit and um help persons become speech language pathologist and in addition to that once they made that decision to work with person that are very severely involved in terms of their communication needs cause that's really what we're about.

Dr. White wanted to emphasize that she does run the bilingual/bicultural so if there are parents who that you know if it convenient for them to come to Fullerton we do have a sliding scale and step. It doesn't take Medicare or Medicaid so that may be problem for some people, but if it seems like a good thing.

We appreciate the opportunity to be here

MH You've just given so much information. I really appreciate your honestly and your willingness to share and trust us and trust the cameras.

Focus Group with Related Service Personnel

April 19, 1996

Nancy Dunn, M.S., C.C.C., Moderator
Arkansas Easter Seal Society

Summary Background Information

Type of Group: Focus Group of related service personnel.

Number of Persons Present and Roles:
Jade Bolton, speech language pathologist in the Little Rock school district who serves Fair Park and Terry Elementary school; **Deodis Fleming**, speech pathologist in the Little Rock School District who serves Miss David O'Donnel Elementary and Dunbar Junior High; **Katherine Boyd**, **Kena Gary**, and **Vera Cole**, are all paraprofessionals in the classrooms at the residential center at Arkansas Easter Seal Society. Ms. Boyd works in the Early Learning classroom and has been there for 10+ years. Ms. Gary has worked in the Intermediate classroom for 2 years. Ms. Cole has been with Easter Seals for 8 years and she works in the computer lab in the classrooms. Moderator knew all participants casually.

Date Conducted: 4/19/96

Where Conducted: Augmentative Communication Lab at the Arkansas Technology Resource Center at Arkansas Easter Seal Society.

Logistical Issues: none

Modifications Required in Protocol: none

Synthesis Statements

1. Family Goals and Expectations
    - Parents want AAC device to facilitate use of oral speech
    - Family is excited initially regarding AAC
    - Expectation change after receipt of device
    - Child's ability to communicate across settings is limited due to perceptions of others and extent to which child can use the device independently
    - Families come to realize that child will not make progress as rapidly as anticipated

2. Positive Impacts of Devices

- Family becomes more involved with child
- Parents can better understand child's needs and desires

3. Negative Impacts of Devices
   - Families experience frustration in presence of inadequate training
   - Difficulty in moving devices with in environment
   - Programming attempts may be made with inadequate training resulting in loss of language

4. Family Responsibility
   - Family must assume programming responsibility for use in specific contexts
   - Must ensure device availability for child to use in community

5. Impact on Family and Routines
   - Device may generate jealously among siblings
   - Changes in family schedules will be needed to accommodate the child
   - Time is required for programming
   - Stress is generated when families are aware of more recent technological advances, but cannot consider due to funding concerns
   - Families may blame themselves when AAC isn't working and become defensive
   - May prefer to use a different language on device at home than used at school

6. AAC and the Community
   - Devices not used in community at all times
   - Children are limited in ability to communicate with others without devices

7. Families and AAC Decision-Making
   - Family wants child to be working on age-level activities
   - Families may not understand speech output of some devices
   - Families should be more involved in AAC decision-making
   - Observations of child in natural environments is needed
   - Need to see range of devices
   - Need training in programming
   - Need hands-on
   - Must make conscious effort to be involved in decision-making

8. Issues not Considered by Families
   - Voice quality not natural on some devices
   - Numerous button depressions sometimes required to express a single thought
   - Families don't consider linear process of learning to use a device
   - Small steps toward progress may disillusion some families

- Some children will want to use device immediately and be resistive to training

9. AAC and Professionals
    - Professionals must closely examine family and identify devices appropriately
    - Families should clearly communicate their expectations regarding AAC
    - Professionals share a common value-wanting child to learn-with families
    - Open lines of communication are important

Transcript

I'm Jade Bolton, speech language pathologist in the Little Rock school district. I serve Fair Park and Terry Elementary school.

My name is Deodis Fleming. I'm a speech pathologist in the Little Rock School District and I serve Miss David O'Donnel Elementary and Dunbar Junior High.

I'm Katherine Boyd. I work for Easter Seals and I am a paraprofessional.

I'm Kena Gary and I'm a paraprofessional.

What was that?

Kenya

I'm Vera Cole and I also work at Easter Seal as a paraprofessional in the classroom.

ND What do you perceive the goals or expectations to be for families with children who want AAC devices that have not yet received them? Do you think that the goals and expectations change after they have received the devices? and in what ways?

Um, your first question was what do they perceive?

What do you perceive their goals or expectations to be before they get the devices?

I, with my family and the experience that I had they were not too receptive to the board, but they realized that they had no alternative. At first I think their perception was that they would get the board and it would be ah, a mode by which their child would learn to communicate orally. And that was the way they looked at it initially and then eventually I ah, they began to notice that their child possibly wasn't going to communicate orally and now I see a big push to ah, is she getting the training that she needs? Ah, is she doing, ah you know, pretty well in the sessions? But at first it was like well we are going to do this and this is what this is going to add an adjunct to the oral communication and eventually she is gonna to talk. And sometimes that does happen, but they had saw the change as time progressed.

Well, with my experience, um, talking was not a realistic prospect and the family was aware of that. I think initially there is, um, there is an excitement, um, because it is an opportunity for the child to communicate on their own. I think what happens the expectations do change and you realize that in different environments it limits the use of the device and because you're involving training of your environment and people, um, and also you realize that, um, there are other obstacles, um, such as, how it is perceived by others, and um, will this, will they be able to use it on their own and that kind of thing.

I do think that the expectations do change once you get the device and in my case I think they did, you lower your expectations once the device is received.

Sometimes, well I feel like we see a lot of excitement, you know, because we are doing basically doing the training the education department and it's like we are turning into a museum, we have more children that likes to like come over and help and join in and you know, because they see it as, I don't know if they see it as a game or what, they get involved also not only with the child that's doing with the device, but you know they get to do it too and it's just a lot of excitement. So it's a learning process really.

ND Do you think it changes are after they get the device?

After a long period of time they have that same board with the same pictures on it. It's not going to change or elevate them to an another level. They kind of break out and go okay, lets get out the board.

ND In what way, if any do you think in AAC device positively effect families?

I think, I think that they are able to communicate better and you know everybody is getting involved and once that child sees that he can't speak or whatever. You know seeing that everyone in there is trying to learn also that gives, you know, you more incentive to go ahead and learn this, you know, themselves I think.

I think it's good too because the, the parents and the children be able to communicate with each other and they be able to know what the child, their wants and their needs are.

ND Do you think that there are any negative impacts with the AAC device in the family?

I don't think so.

Ah, but one that I guess that I've seen that immediately came to mind are um problems with the device. Or ah which has happened in my situation. Um, so it's probably more mechanical then anything, but that is a frustration in the home. I find that family members have when the device is not working correctly. When for some reason there is there is a malfunction or um everyone doesn't know exactly what to do to make it do what you what it to do. In other words, not being fully trained um, for all of the different things that it can do. So I think that would be the main frustration that I would see in the home.

Just to add what Jade was saying, I know that on um another barrier that I have seen with one board is the ability to move it around. For example, in my case both of children that I am working with um they are involved motorically and one of them has a walker and the other is involved upper left side hemiparesis. They cannot get those boards around. We are looking at now, the child with the walker um to get to obtain a lisel walker to put that Liberator on so she can get around and use it. Another problem is that um the family um tries to program the stuff themselves and I saw that sometimes when I let them take it home for the break and I can tell that they have been fooling with it. That maybe good, that maybe good because they are really trying to get actively involved.

ND Have they been to training, like formal training?

You know I don't know if they have previous to my seeing them and possibly they have and um but I know when I have seen them in the list home, I put the symbols of the um the I can't explain, yeah, the icons. I'll put the icons out to the side of that is apparent with the phrase and so they know exactly what icons goes to program things and so it's pretty easy to figure out.

ND Do you think it would affect families um for the roles that family members must assume for the AAC device?

Well, definitely because they would have to be actively involved because they would have to get the training for the device. They would have to program it for the needs of the child or the person at that time. You know they would have to have some motivation, otherwise it would it would I think that in itself would involve um the family members in it otherwise the only information or the only input would be what the service providers put in it. It would only be used when they are with their service providers so um it does encourage participation with the family members.

ND Do think it that it would affect the organization in the home environment, you know having the devices?

I think it would.

Group laugh.

You know, like ?? ??when you get a Walker.

And you forget, and another person might come along and say, well they left the thing unplugged and it needs to be charged up.

And you have to think all of the kinds of situations where that child is going to be in that we just take for granted. Even in the school situation the teacher or the aid they'll forget to take the board to the cafeteria or they forget to take it to see the other therapists. As a therapist I am like where's the board? You know get the board. You know use it in these situations as much as possible and it definitely has an impact on the lifestyles and situations. It really does.

ND Do you think it would effect the relationships with the family members?

The relationships

Sometimes the child might pretend he was ??wrong?? when the parents are not around or the children.

That is right.

You know you take regular children to the grocery store and definitely you know, just when and your child there. He's disabled and you know you are going to take him to the grocery store. So you go to the grocery store and you say you know what do you want to eat for breakfast cereal and he can tell you.

Or it could be used the very opposite, your child has a disability is not taken to the grocery store and is not included in on

What do you want and that kind of thing.

and it is a lot easier to do what you think what the child needs or so it could be done both ways. It could be a positive thing for the other family members or it could be um you know a little jealousy.

Because it take away from other children you have to constantly you know not

More time involved

Yeah, to take away time from the other children to you know keep constantly doing things for this one child the other children might feel a little jealously.

And another thing is that as far as when we were saying about ??opt ??One of, well both of my families, the main thing that I thought about was a lot of functional types of things. So she could realize that immediately that this was really gonna serve a purpose for her and we did not do anything academically at all, until she, a lot of functional types of things, go to the bathroom and so she can just form attachments.

ND Along that same line. Do you think that it effects the demands placed on that child and the time of the family members?

um huh

Because if one child wants to do one thing then they say well then the time cause we have to go back and do this for this child. Everybody you know have to schedule it so that it schedules it around that child doing some certain thing. Other children they do regular things and they take for granted you know, running, jumping, and going places and you know, walking up and using the bathroom and they have to take the time.....

ND Do you think it would effect the levels of stress that the families experience?

Yeah, because it is time consuming sometimes.

And when you think about the Dynavox, which is one of the big disadvantages out there. One thing that I don't like about it is because it takes time to program it and to put in information. It's not something that you can do spontaneously at the moment and I mean it takes me a long time to get in a sentence. And so, um, I can see that. I mean I experience that at school. So I'm sure that's a frustration at home. It's a functional tool and it's good but a lot of limitations to it. Um, you know at home.

ND Do you think it would effect the relationships that family members have with others particularly out in the community?

Yeah, everyone is not that understanding as you are and if you were a mother with a disabled child cause your child's?? ?? and bathrooms are not always equipped, you know, and in society we really don't have things like

It's also the kids out ??

I'm in a CDI class so we go out, but we don't but take out the devices all the time. We took them to the zoo one time but a couple times Different places, but we don't do it all the time cause some of the kids with the devices they don't go out all the time, but they do go out and everyone go but we just don't take all of the devices with us.

We are just getting back into the program of it because we haven't been using those devices. So it's know since Ginny and John have come over and helping us with it. If it hadn't been for Ginny I don't think. Well anyway, yeah, she need a big pat on the shoulder. She helped us a lot and we are getting back into that and um, I really enjoy because we are giving more of the children. We have gotten away from a lot of that, that those children now can talk to us and they has been more, you know, excited about it. So I think once we get back into that feel, we can use those devices and somebody in that field can, whatever, they can still, you know, talk to other people because even when people come up and try to speak to them. They have no way to saying anything, but they understand, but you know then we have to go up and say that they can hear you and they can understand you, but they just can't speak. Then you know we have to teach them their understanding about it and still talk to them more about it and have a conversation with them. So I think that it would be better we you know started back using the devices.

ND And the next question asked do you think that having a device would effect the families ability to take their child into the community? Like eating in restaurants or going for recreational activities.

But normally would they have a device? The boards or those pictures, the one that can't afford the devices so those have been pretty helpful to so, you know.

Which by the way, since we are mentioning it another stressful on the family. You asked that earlier. I thought of it later and you'd gone on to another question, but that's a big stress on the family. The financial obligations and empowerment that are constantly, constantly there because you know when a child, you know, you try a child with a device. He does it awhile and then something new or something better and ah so we tell them about this new device and you know it sounds great. You know every family is not as fortunate to um have either assistance or financial um income to readily go out and buy a $5,000 or $6,000 piece of equipment and so that's s bog stress.

ND Um, what do you think are the greatest concerns you have encountered when working with families during the AAC decision making?

The stressors of the family?

ND concerns

The concerns of the family.

Now, with both of mine I was not involved in that.

ND Describe the roles of families members. What I guess whatever y'all, just your opinion, what are the roles of family members during AAC decision making processes?

To ?? ?? their goals

To be on their school level cause Adam's mother uh oh, one of the client's mother was concerned about him being on his school level.

ND So their opinion should be taken into account?

um huh And she wanted to know was Adam gonna be, was he more gonna be okay, like this school grade and was he going to match along because he didn't have one when he was at this school. Like he didn't have one at all and half of the time he would say something and they would not know what he was saying at all. And they just wanted him to be on his school level.

I think that one thing too is that if they can understand what the device is saying, because sometimes you can't understand what it is saying. I mean we have Otwell speak for me. I also heard the devices that I had the slightest idea what they were saying. You have to keep asking the child to, you know, play it again or either, you just, you know, try yourself to figure it out so I think you know is the voice any clearer or something like that.

Another thing I understood. ?? ?? I think the way that the families could be involved in I guess deciding which board to get. I think they should be interviewed extensively and um possibly someone should go within that persons environment and naturally see because perceptions vary. The examiner or someone go in there and actually see what is going on and they will have a tendency to be more objective as to the strengths of the child and the weaknesses of the child and really trying to custom fit that board um or that communication device for that child.

ND Describe things about AAC devices that tend to not to considered by family members.

Um, the first thing that comes to my mind is the voice. You now, even though there are different voices on those boards most of them have and they most of them still do not sound real and doesn't and that bothers me and I don't know if ever if there ever get that, you know, but just the mechanics of it and then that sometimes children get frustration because they have to go through a series of moves to get one response and it's and if someone is talking to them they have to stop and look and digest and then try to find it especially if they have a lot of motor involvement so I, those are the areas that I would think that they would affect.

ND Anything else that maybe is not considered of the family members?

I think, um, maybe some parents don't look at the process as A, B, C, D, they look at the D, you know, my child, if I had this my child would be able to tell me when he had to go to the bathroom. Tell me he wants water. He'd be able to all of these things, yeah, but they don't understand that it takes awhile, it takes awhile and ah, you know, it's going to be baby steps all the way. And I think that there is some misgivings on that part, um, what the true expectations are and so there is a let down once you get the device. Once you start working on it and you're excited because he's finally able to push the button, you know, but that is a success, but you know, you have to look at things in baby steps before you can I think that may be it, a let down.

Just to add on to what Jade was saying is last year my child that was on the Dynavox. We fought the whole year, I mean, there was no such thing as getting him to sit down and do anything constructive and learn. The only thing I could was just let him do is push the buttons on it. That's what we did for most of the time, you know, I would try to sneak stuff in now and then, but for the most part, it was like he wanted to do it his way. This year it was completely different. Me, I did not ?? chase him?? with the board. He knows how to point and identify and say "Hello", first and last name, but last year there was no way that I was going to get that done because it was something that was new to him and so he had to get it out of his system. It wasn't like Jade said. It was like okay we got it so now he is going to start communicating immediately and it wasn't. There are other variables that's always involved.

ND What advice could you offer family members on how to better work with professionals who are trying to identify an AAC devices for children? What advice would you offer the family members on working with y'all as professionals on how to identify an AAC devices for the child?

Yeah, it is like I was saying awhile ago, you really have to study the family??...........??
ND And so what would you tell the family?

I think that I would want to find out what are your expectations, tell me what you want for this child to do. Once I get an idea of what they are saying I can deal with the reality at that point. If they are saying, well I want them to be able to one day to do this, this or that. Then I think you can start limiting your choices and your devices, um, which ones you think will help the child do that. Is this child physically capable of doing that? Will this child ever be physically capable of doing that,? So um, once you see what they are thinking and be totally honest and just tell me what you see happening with this child communicating? What do you want him to be able to do? Then you can kinda narrow the scope a little bit, and you can giver yourself choices and hopefully um allow them, inform them a little bit more, so things are more realistic for them.

ND So, the families should tell the professionals what they expect?

What they want, what they want because if your um, most of the time with people who use these devices with children, we have an idea. We look at the child. We see physically they are capable of doing. We see um a little bit of how they are going to be able to use this device. We're already thinking that way. You can take this out. You'll be able to go home. We're already thinking that way. Parents a lot of the time don't, but this is something that we're trained to do. We do it all of the time. Parents this is their first experience with these things. They don't know, they are not around it. They have no idea. You tell them that this is going to help the child communicate, oh okay. To them communicating is, you know, pushing the buttons, talking, you know, those kinds of things. To us it might be something much smaller, so I think I would want that parent to give me what their expectations are, what they see, and that way that would enable me to help guide the parent more for realistic expectations.

ND Do you think that the values and beliefs of the families are different from yours?

No, I think we all want that child to learn.

ND What changes are needed in the AAC decision making process to make it easier to work with the families?

You might want to give them an inservice, just to invite them in and see, you know, get some devices and different and how, you can get them up to that point where to program, you know, some devices, you know, maybe different children, they can, you know, help in??.........??

Maybe just give a workshop and work with in.

Or allow them ??.....?? when choosing ??.....?? to check it out, take it home and try it.

ND Think of a time when you worked very well with a family and a time when you didn't. Can you describe what was different from these families?

The closest thing that I can think of that comes close to that scenario is when I first met the family, they I mean they had a chance and they didn't fully understand it and they were in a position of blame because their child wasn't learning these things. When I saw them they were pretty defensive and I saw him initially and my goal at that time was just to calm them down and eventually at the end of the school year they were more favorable of to ??.....?? what was wrong.

Um, in recalling not as positive it probably related similarly to the Deodis's experience, they had a bad previous experience. They transferred that over to me, probably all speech pathologist at that point. So they were not very receptive to my suggestions or comments and they were pretty negative about other aspects of the child's care as well and not just that. So consequently, communication was not very good. We did not have a good rapport. I was not comfortable and they said as little as possible and um, it happens, I mean, you know, we don't prefer it to be that way, but it happens occasionally. Opposed to good relationship were you have open communication. You voice your concerns openly and their excepted well, whether that is I don't like what you are doing or I think you are doing a great job. I think that helps a lot with the positives on the device, and just keeping that communication open because you just assume that both parents and the caregivers or service providers that they are thinking what you are thinking and a lot of the times not. I know that we have been at conferences and the parents will bring up things and I thing this is what they want. I realize at that point that um, I was not focused with something else and they were wanting him to do something else at home and we find this out at a staffing or months later. You can really keep that communication open if you'll get comfortable. Get to know the parent. The parent get to know you and talk it out and work together that helps the relationship.

ND The other thing that I wanted to throw in is that you work with a family with another language and what the child does that works with the device?

I think that maybe a stabilizing influence since they, because the abrasions at risk some of them are at the brain stem and this to but they are not intimidated to affect speech we as if you were just talking to them there are a lot of different areas. Words that mean the same , even in this country, but these family is from another part of the word and some Venezuela as well is there. We really have to make sure that we are precise in what we are saying, very precise. Nothing symbolic or slang cause if can be ?? ??or ??......?

ND Do they store in your language?

No and that's why, that's what I was saying this is more like a stabilizer for us, because she is having to use this in the English language. They do speak ??Arb??. They say they don't, but we have a strong feeling that they are using their and they is nothing wrong with that in their home. Their home language because they are times when the child is trying to communicate and it sounds like ?? ?? to what she's saying, but we don't know what she's saying. It sound like it really some profound significant word here, so that's what we came on this child is probably speaking their language that they speak in their home and so that board is sorta like a bridge that we all ?? ?? go to and she know what we want for movement on this board and they know, we all have a common ground the Liberator.

ND Have they

We haven't got that and that would be an adjustment. That would be an adjustment if we ever get to that.

ND You have any other comments about how AAC affects families?

I just think that if you ?? ??all of the time even in everyday situations ??....?? not mention their other children. They'll say I'd rather do it myself or they won't even allow the other children to have the experience like involved in something at the home. That's just for regular children and then when we get a child with special needs they develop a possibility to give up rather that challenging this child to express communication. So I think it teaches that family members that they have to ?? ?? They have to have a very conscious effort and to engage that child in everything as much as possible.

I know that I think we have to teach families to appreciate the littlest amount. The little, smaller things and then um you know we eventually I think look forward to other things at well until appreciate what's you've got. Appreciate the little things you know. I can see that happening. Especially if they started out much smaller

To be involved

To be involved, everybody from the little one cause everybody can take care, just one is the family and everybody had to take care not only mom and dad, but other brothers and sisters.

Focus Group with Chinese Families

April 22, 1996

Mary Blake Huer, Ph.D., C.C.C., Moderator
California State University-Fullerton

Summary Background Information

Number of Persons Present and Roles: Ramona Tan, Chinese psychology graduate; **Julie Doan**, Vietnamese BS student in communication disorders; **Edith Le**, Chinese professor at California -State University-Fullerton; **Lilly Rhee**, Korean undergraduate student in communication disorders at California State University-Fullerton; **Fengchen Tan**, retired Taiwanese High School teacher; **Greta Tan**, daughter of Fengchen Tan and translator, first-year graduate student in communication disorders at California State University-Fullerton; **Juliana Tan**, 49-year-old Chinese mother of three daughters

Date Conducted: 4/22/96

Where Conducted: A classroom on the CA State University-Fullerton campus.

Logistical: A translator was used for the mother-Chinese. The daughter translated. Only consent and demographics forms were completed as these individuals did not know about AAC. They talked about their culture and their perception of persons with disabilities. The family members talked about their cousin with a disability and their life experiences with this person before they died.

Modifications: Only modification was the elimination of the questionnaire as it took too long and was not relevant to these individuals.

Synthesis Statements

1. Disability in Asian Community
   - Persons with disabilities are not topics of discussions
   - Asian communication-holistic -no one desires to be different
   - Persons with disabilities are segregated
   - Children with disabilities viewed as burden
   - Death can be seen as relief of burden/disability

2. Training Issues
   - Father suggested working with families of Asian community
   - Profession should use native language of families

- Persons with long history of not communicating would not be inclined to get/use service
- Help families understand AAC interventions take time- long term commitment

3. Access to Families
   - Use of liaison who speak the language
   - Need for more dissemination
   - Dissemination through Asian newspapers/media
   - Use of word of mouth in community
   - Helping people to speak English may be strategy to develop rapport.
   - Let them know services are free
   - Go to Asian community doctors
   - Seeing devices helps acceptances
   - Utility must be made apparent
   - May be perceived as unnatural
   - Families will vary in acceptance

4. Partnerships with Professionals-Decision Making
   - Families view professionals as authority in decision making
   - Reluctant to discuss problems, say how they feel
   - Families want immediate results
   - Keep communication open-continue to ask questions-provide explanations
   - Understanding takes time and patience
   - Need both verbal and written communication
   - Want to know services will continue, not one time event

Transcript

My name is Ramona and um I have just graduated a university with psychobiology degree. I plan to go on with my professional school career as a student and um I'm Chinese. I'm 23 years old and

your short

and that's it

MH and if you speak a language other than English

I also speak Mandarin, which is a Chinese dialect

MH Well, I'm really glad you came here today and I really appreciate, it's kinda neat to have a family of four. This will be most representative of a family that we've had to date and that's gonna be nice to kinda see different perspectives with in a family. Okay, next

My name is Julie Done and I'm a post baccalaureate student in communication disorders. I came here from Vietnam when I was about three and I speak Vietnamese fluently and um that's about it.

My name is Edith Le. I'm a professor here and I came, I was born in Hong Kong and I came here at one Europe age and I speak conversationally a little bit some Cantonese and some Toysonnese.

Hi, my name is Lilly, um I'm Korean I came to American at the age of seven. I'm an undergrad here at the communication disorder. I speak Korean and English fluently. I write Korean.

MH Okay, great we've got a nice group here. My name is Mary Blake Huer. I 'm a professor here in communicative disorders and um speak English only, kinda an outsider in this group today. I teach in the area of augmentative communication and I also deal a lot with technology and we said I'd be very happy to show you the lab and some of that part of our curriculum. I'm also the project director on the grant here that some of the students are on.

Hi everybody, my name is Pham, that's my family name. My given name is Ping Cheng, I come from Taiwan, I'm a retired high school teacher. I majored in education and ended up teaching English as a second language for nine years and before that I was a solider. My um for the Chinese Air Force. Concerning the disability, I in the communication disability that's the first thing that I have ever heard of I had never heard of this in my own country so it's sounds very interesting to me and ah in order to make myself understood to everybody I would if necessary I would Greta, my daughter act as my translator. I don't think my English is good enough.

MH I think your English is fine, but certainly if there's a particularly perception that you'd like to have, that you'd like to comment on more fully and you want to have Greta augment that certainly.

Actually, I think that myself is ?toe vag man cue ves?? I mean um technology and ah very professional subject. I understand, I think that I understand the truth of this meeting, but I wonder whether this a panel or a sandman of community. You see people like my wife and myself I don't think that we understand anything about this. I, my wife and I might be able to answer questions if we know. I think that the only thing that we can do here to help you and Dr. and all of the other ladies that's what I have indeed?

MH Okay, it's certainly, certainly it isn't a panel or a seminar. It's a conversation and I think um I'll be, I'll look forward to hearing your comments and perceptions. So thank you very much for coming.

your welcome

My name is Anna Pin. 1986 I came American I was 49 years old. I have three daughters. I'm proud of my daughter. I' very happy to join this meeting an I speak Chinese and ha

Well I'm Greta. I'm a first year graduate student here in the com disorder and um I'm on Dr. Huer's grant and um these are my parents, this is my sister and I'm glad to be here. I speak Chinese fluently that's my first language.

MH Okay thank you, the first question that I would like to ask is in all of the various experiences that each of you have had, um what have been your experiences with persons that have had any type of disability communicative or physical, mental um what personal experiences have you had.

I can give you a first hand experience. I have a cousin who's mentally disabled. I think manic, but I think it was never talked about she was kinda you know brushed aside, ignored and um and it's just common for us not to ask questions and not to relay further answers about her. So it's basically hush, hush sometimes with any type of disability.

For me too, I in society, a holistic society no one wanted to be different. You wanted to be one or the other. You want to be the same. What had happened was my friend's brother, he was dyslexic, no he had a down syndrome, what they did was they put him in the hospital and he was never talked about. Somebody asked how many kids do you have. He say oh, I just have a daughter. It was never talked about. He's go visit him only once a year. He'd pay the bill and that's about it. If you have a child who's handicapped or any kind of disability it's not really you know they don't really include them with the family. They send them away to a hospital

MH Any other experiences?

I have a cousin, she was born with cerebral palsy I think. She was always included with the family. She passed away when she was seven. This was almost 15, 20 years ago, and she was never talked about after that. So basically, when she was with us and everybody put in a lot of care. She was always included in the family, but after she was gone we haven't mentioned her in the family for years.

My father is blind and he also lives with us now, but I've noticed he's been blind now for a number of years oh about 20 or 30 years and ah when we go to family gathering with relatives and so forth they treat it as kinda very natural he has a disability and he's included in all the activities when we eat or sit down. Everyone makes sure that he has plenty to eat and makes conversation. Treat it quite naturally. He's included in all the actives. One thing that I think we know that he's had medical treatment because we've been in this country and as he was disabled, but there's not a lot that's made of him besides the medical part there's not a lot to deal with the therapy or the socialization, not a lot of formal counseling or therapy that's done I think in the Chinese culture besides the operation, medical treatment the rest the family kinda takes care of. the mother takes care of or other relatives, they treat it as a very natural part, but they do not seek a lot of counseling therapy outside of the straight medical.

MH Any experiences?

Well, ah I would like to ask something to ah the unfortunate ah niece that's my niece. My sister's daughter, second daughter and ah and it's very sad that all family have a big burden of disabled child. Almost ??grateful?? child. She was unable to move. she was crying sometimes. She was able to smile. She was not able to speak and express herself. I think she died at the age of nine not seven. It's a very, very, very big burden for the family. To all her relatives, besides her parents and brothers and in our country nobody pay to much attention to disabled persons we just wait for the relief that for death. Nothing other than that could we do and ah we do not have the concept. Her mother, that's my sister, and her father, my brother in law took the child, the sick child to see all most all of the hospitals and doctors in, but unfortunately nobody could do anything about it. We just wait and wait and ah we tried everything possible to make the child, make the child feel comfortable and ah our neighbors and all the other friends just showed their sympathy, nothing about, nothing more than that can, could anybody do and ah that's because of our ignorance in our government. I mean some charity organizations and any other people um pay much attention or offering assistance to I mean a disturbed family like my sisters family and ah they almost exhausted their money, their energy, their emotion, they just suffered from the sick child and ah nobody ever mentioned to do any therapy or anything about it just some medication to make her sleep to cry less, things like that. Well, I think it up to because our I mean our being so behind the modern technology and not event he doctor know anything to do about it. Like I just mentioned the only thing we could do is just waiting to be relieved. That's the death of the child. I would say that's a very sad, very tragic to the family. I think that's 15 years ago.

MH Any other comments? Than you for that. That's very insightful I think in terms of sharing that. The, what's happened in about the last ten years in the United States, probably the last ten years is this new area of study that's developed to help persons that are very, very physically challenged. Such persons used to be kept at home in the United States as well, and then know increasingly have been able to go to school and have educational opportunities and that's what we work with here. That's what our training is about. The problem, maybe not a problem, the issues that we're seeing are if we find a child that's severely physically challenged like with cerebral palsy are people familiar with the term cerebral palsy or if the persons in a wheelchair. If they can't use their hands and legs. If they can't speak, ah we try to work with that child and that family. The question that I have is, if the family is Asian and here we have Chinese, Korean, Vietnamese represented how can professionals help those families? That's really the ideas that I'd like for you to brain storm about with me today. As a trainer I would like to prepare students to go work with families, so that it's meaningful and it's useful and it's appropriate and I don't really know how to do that, um I think that sometimes there's a division between the family and professional and it may be what the professional is suggesting isn't always appropriate for the family. I'd like for you to think about that with me for a little bit. How your individual cultures may be more open to speech language pathologist as a resources or may feel more comfortable having conversations. In other words, how could we help families not feel so desperate or have that sense of waiting as professionals? Is that a clear question? That's kinda what I would like for you to talk about and share with as far as your personal experiences, cause if we go in and say this, this and that, that and leave. That's not really useful and meaningful. That's really the purpose of these focus group to really say to the family talk to me, teach us. Then I, my responsibility is to train students to be better professionals, better clinicians, better therapists. Does anyone have comments?

Yes, yes I think that even thou I do not know whether I am right, but I would like to ah to state just a suggestion. Let's see if understand you professors have some grant your working a grant project, I wonder if it's practical for you to choose some Asian families that have disabled children or adults to assist one, some of your students to work on that person as a realistic and practical experience/experiment and to see how well and what result you can get from that experiment. So that you can accumulate your experience decide therapy professional theoretical practice.

MH That's a good suggestion. We have tried to do that or we are trying to identify families where they have a disabled child or adult in the family. What's been real interesting with the Asian families that I've met is they have not felt comfortable with me or with my students to allow to have enough trust so that we can work directly with them. So that's the purpose of this grant, is to have students work with families, but it's my perception and I may be wrong, but it's my perception that the Asian culture is somewhat closed and somewhat confidential in wanting to keep there children and adults more in the home. It's not as public so to have a student assigned has been an issue. It's been difficult for me because the families don't seek services, nor do they feel comfortable perhaps in having that, maybe they feel, maybe there's a feeling of invasion into the home. I'm not sure, maybe you people could help me identify what those issues are, but that's exactly what we're trying to do with this grant. Students such as Greta now are on the grant and that would be a wonderful learning experience for her, but we're finding families are cautious and maybe not comfortable ah and maybe not open to us doing it right now. So maybe the approach is wrong and that's kinda what I'm searching for today some ideas.
I think I understand your frustration. The frustration your being faced. I agree ah some of the Asian families are very conservative and sometimes they are timid and they have the complexity of inferiority and ah I think it's not a major of frustration or barrier for you to break through if like you have students of different origin like Chinese and Japanese and Korean. You can assign your student and your students to as not a direct approach to those families as your students can use their language so that they can make them not so timid or so ashamed of their tragedy. I mean ah that's the a family that ?last?. Make them not to fear, not to feel so desperately and assure that you are eager to help them. I think that would be a practical approach to those families.

MH I agree with you and on the grant we are trying to have students who represent different cultures and students that speak different languages and faculty that are all different in our own origin ah and experiences so that we can reach out. So certainly I appreciate that, I guess the next step that I have to also think about that there are so few Asian students that I also have to train other students and I want to be able to train them correctly with strategies so that they to can be successful in meeting the needs of all the persons that they meet. That's where there's sometimes barriers that I hope to identify and overcome and work through and etc. etc, but I really share your ideas. It's that next step when you leave the immediate community where I'm running into some frustration and I don't know if you have strategies or other personal ideas that might allow us to open up or be more appropriate or little steps. That's kinda my goal, so we have, it like there are some other problems here.

I may be wrong, but I was thinking, is it possible to make use of family members of your students. Such like, for instance like me. I speak several Chinese dialect like Madarian, Cantonese, Taiwanese and Hong Kong, quite a few dialects. I myself having some teaching experiences and ah I also because I'm a retired man and I think I can spare my time if I can be really helpful to help my daughter, your student.

MH Boy, I would greatly appreciate that.

Just as a volunteer when it's necessary and when you think it's useful and workable if I'd be grad to, my wife maybe.

MH We're looking at Chinese characters, some of if people can't speak some times they have picture or symbols and we're looking at Dr. Le and myself have started a study with Chinese writing to try to put the writing with the symbols or pictures to help meaning and so that would be very helpful in terms of translation. Her mother is helping us in terms of translation. It's clearly a family affair. So I would appreciate that.

Like I mentioned before, men like me and person like me is a total laymen and so many technologies, I mean technologies are totally new and ah I just doubt what I would be able to do in translation especially if your professional translation.

I think that the social part that you mentioned is really important that your students and family members could help with that initial meeting. Getting the door open, the willingness to look into maybe participating in the grant or participating in the therapy or seeking help is sometimes to gain peoples trust. I think that they fee that they have to know to, someone who is similar culture, similar background, similar age, experience they are more willing to listen, to open up to see if there's a chance to interact.

I think the hardest thing about Asian culture is that they don't realize that they are therapist out there that can help them. They don't even know that there are communication disorders, speech therapist out there. So I think the key is to educate them and help inform them that these services are available.

MH How might we approach improved information dissemination? What strategies are available for us?

I have, the Chinese community that I'm familiar with we do read newspaper and that's sometime easy, that show the information and they are professionals in different areas that would write columns and maybe that's an approach and we can starting communicative disorders and how you identify these problems and how professional sources are available to help them maybe a monthly, maybe a weekly thing. You can open to the general public for their input because a lot of family are very interested in how to speak English well and they see that not being able to speak fluent English as a disability. So we can start do accent reduction and gradually work toward clinical pathological origin of disability. Then maybe have them start just have them be familiar with our services.

MH Those are good ideas in terms of cause it's hard to reach and the flip side is if you make a service aware we have to at the same time be training students to respond if there's a telephone inquiry which is multicultural gets operational and the AAC clinic will go more and more multicultural as have students trained to work on the grant to meet that need. I wouldn't be very useful with persons if there were a language barrier, but I could certainly train in terms of the technical professional jargon and content, but clearly if there's not a shared language then the communication there would be clear information that's being transferred I think. I have um, are there any other comments on that topic.

I think that what Greta was saying about using the newspaper and perhaps other services as a type of referral ah could be almost like a grapevine effect where I think many people you know they say close in a community trust people who they know. Once you get out and someone perhaps refers and word of mouth gets out. I think that may be one way, just having call and say hello we have a program are you interested if a relative or friend has already gone through and done something like that then reduction or association they are more likely to respond

I think the key with again through about the families in the Chinese community. you have to probably let them know that this is a service where you can help then speak English better or more fluent. Lot of family come here, their primary concern is how to you know how to integrate into the main stream society. You know one key strategy is to be able to speak English well, so this may help them to realize, be aware of our service.

MH So if a family had a person with a disability within the family. A more positive strategy might be to help that family were interested in improving their English skills in terms of enunciation before you would help the family.

Exactly cause

MH See cause that's the kind of information that

I was thinking that you have to be able to communicate with the family before you can reach the disabled person and if you want to gain interest you have to help them to know that you can help them improve their language so they can communicate with the professional and not feel intimated or threatened

MH That's an interesting strategy. Thanks for sharing it. Dr. Le is going to have to leave in just a couple of minutes to go teach and when you leave just fill this out and put this in my mailbox sometime. So I'm going to jump ahead to another question that I want to talk about and then I want to go back to this topic and have to speak to maybe to differences, cause we have several different Asian cultures represented and if you perceive their subtle differences um I'd like to have you share those as well. Let me jump onto another topic that I know Dr. Parette is interested in and that is how do does the Asian community perceive technology? Okay, how does the Asian community perceive technology? um and there are a lot of differences in reaction to the use of technology and we'll take it one step farther after we talk about technology we'll talk about using technology for communication which is kinda another layer. Does anyone want to speak about?

I would like to say that concerning strategy I think the most important thing is to make known you are able to and you are willing to offer service, free service for language barrier for the family, having language disable members that type of thing. That's um I think that's the first thing is to make yourself known to everyone with that and the second you gain um their trust. Which means their confidence in you and then through this you can give the problem access to them to reach them and to show that you are able and you are enthusiastic to help them. Not only for the interest of academic or professional practice or training you really want to help those people. I think it would be workable.

I think informing them is a good point because technology at least in my family the old generation is not something that they are aware of. They are used to perhaps a holistic view of medicate, like herbal medicine or perhaps something that does not rely so much on modern technology or even that they are using.....

Well, they need education. You see they need time and education to understand to build up their perception. They know nothing. They're ignorant an ah I think they are very money conscious. So that you, you have to make them know that you are offer services that's free like some charity organization.

Maybe a trial period to see if they have the device. They could try it.

MH What do you think about computers?

I think sometimes it's easier things like computer to introduce like the younger generation of the family and use them as the bridge the younger generation for them to introduce to the older generation so then the older generation is not a fearful as ?a known? for them in a way. Some people in their family are using it and by observing them and kinda just having the technology be around in their environment is way of opening their acceptance to actually utilize it later. So

When I have ??children?? see more technology used they're more depressed. They think it's better. They are willing to put you through that program or that you know that program that ?? ????? lots of noise

MH What do you think the reaction is to persons where they would have a machine that would actually speak, that kind of technology?

Well the first thing they would probably think it doesn't work.

MH It' doesn't work. Why would they think it doesn't work?

Well it doesn't work or not that's gonna be the first question asked. I think that most Chinese, my culture a lot want results almost to think to be evident to spend a lot of money and their time especially to present a lot to the people they don't know about the problem at home. They want result.

MH So it they were introduced t, there's a lot of different, if you, if there's an individual who can't speak. There's an individual where speech, there's just no speech that functional um there are devices now that actually talk that they use that have voices within them. If the person touches it or somehow makes it so that it speaks. It's their voice. What do you think the perception is of such technology.

I think they'll have a hard time feeling that it's not natural, especially if it's not their own language.

MH Can I ask you to expand on that a little bit? You said that it's not their own language. It's not natural. What other kinds of attributes or adjectives might you assign to that. how could you expand that feeling or reaction to that type of technology?

Could ??adjectives?? could we make the machines?

MH Well our profession is developing around the world. It's like 50 countries involved in terms of members. The technology does speak in other languages um the languages the greater frequency in terms of another language use is Spanish and then Swedish and some of the countries where speech has been developed there is less if any Asian dialect that have been programmed into the devices as yet because they Asian community hasn't been as readily available in order to learn it all for services. So that's another purpose of this group in terms of talking with vendors and manufactures or companies that develop such equipment. What might you say to them or what might you say to them or what could we offer them in term of ideas or strategies or would it even be useful if I used the Amish community technology that's not an appropriate strategy to introduce. So my question is the perception of the various Asian cultures of actual technology that would speak for a person. How would people react?

Really welcome technology and so if that machine has the ability to speak Korean that would be even more prone to look, be more comfortable.

My thought is that if they have this physical handicap for long time I think that would have been shut out of the world already so there would be no use for any kind of machine that would be able to talk their voice. I don't think they would be using that. I think if they had a sudden onset and suddenly they couldn't talk one day then they could probably use that. If they've been living with this handicap for a long time I don't think they would use that.

MH Do you think that um if a program could intervene when a child's two years old or three years old would they have been shunned down to use your language by that time?

I think that's the key thing- Intervention

MH Early intervention?

Yeah, early intervention to educate them

MH If we found the child um in the public school, say at six or seven. Would the family still have hopes and aspirations for that child or would they have re-directed their interviews?

Really it will depend on the family, cause I know of a young couple. Their child was born with a disability. I think it was because the parents were eager to know the sex, the gender of the child so they did some testing during pregnancy so that ? inflicts?? some kind of disability. So as soon as the child was born, it was given up for adoption. So you really have to find the parents who are, the young couple that are educated and willing to welcome knowledge about technology to be used.

MH Do you think that if a person were an adult and in an automobile accident and then this technology were offered would there be the same kind of rehabilitation would there be that same kind of

I think they would be much more motivated to so to this kind of technology

MH That's interesting. The, let me jump again to another topic that's of interest. That is the perception of professionals from the cultures perspective. There's a continuum where a culture may say your the professional and everything you say I will follow. Okay, there's another continuum where they may say what a minute, I'm the parent. I want to be involved. I have rights. I need to pursue this. I have questions. I want to participate. I want to collaborate. What are along that continuum, what's, describe your culture and the perception of professionals that

For my parents since the are an authority and you have the education they'll be like whatever you say I'll do, but they don't feel they'll back off. They won't tell you their problem.

They'll just go to another doctor

Because they'll just discontinue it. They won't tell you the problem. They won't tell you how they feel. At first they are more that willing to they'll be able to say that they see differences in the child or any kind of improvement, They don't have patience to wait. It's just like right now. they want the improvement now. If you have that technology they want to see it now. You know what can we do, but if they don't see it they just discontinue it.

MH That was my next question to you. How long is right now? Are you talking a week or a month or a year or? How much time typically? I want to be sure that I don't stereotype a profile, but

I want to clarify something, are we talking about speech therapy or are we talking about?

MH I'm just talking generically about professionals. We could talk about speech therapy, but persons have different perceptions when they interact with professionals. There are different models.

My mom just tells me, she's willing to follow advise your guys words. She said that she would interact with, and find out what they know and ask them questions, but she's also run into so-columnists. My father's professionals thinking they're god and everything and they don't allow to be questioned. So that's her experience.

MH Okay great, are they other experiences. Is that pretty representative?

I think that we generally pay a lot of respect to professionals but also we do have expectations from them to.

Like my mothers case, when she was in an automobile accident and it's taken a long time for her to feel better, even being able to sit here for an extended amount of time and not feeling any back pain. She's had doctors who were really sensitive about different cultural background and language barriers and willing to talk to her and there's some doctors who will totally ignore her existence. Sometimes won't go with her to therapies. The doctor would talk to me directly and say how is she feeling and treating her as just an object. You know there are professionals out there who are just totally not aware of the need of the patient even though they may not speak the same language.

I think that's one of the reasons why. They ?except ? Korea town, China town because for us we don't go to American doctor, we go to Korean doctor because we communicate better. If we go to an American doctor then my mom drags me along to translate and I won't be able to translate every word they way she won't get the treatment that she needs.

MH Uh huh

Do you see what I'm saying?

MH Uh huh

So you can get very impatient.

Yeah

Your time is very valuable for some reasons

Yeah, and they don't really care, they don't really talk to my mother. They talk to me.

MH And see it's that sense of time cause every group has a different view of time. Um in out training program here I don't want to only train one style of interaction. I think that students before they graduate should have a rich repertoire and they should be able to shift that um because it's awful to have a professional there speaking at you when your waiting and you know probably there's not going to be communication. So my next question for all of you is if a person were interested in breaking that barrier. Let's say someone came to me for augmentative and I said okay you should do this, this and this. Why don't we try this and tried it

I have a question, can you explain what augmentative means? So you know we'll understand the terminology.

MH Okay, the term augmentative communication refers to augmenting or adding to your residual communication skills that are in two forms. Residual speech skills, a person may only have parts of their words or just phrases and no more. So they need something to add to that, so they can communicate more fully or an augmentative communicator may only have gestures that are natural or some signs. Again that doesn't meet communication needs so we add to that with either technology or we add to it with communication board or we develop a sign language or . So that's the field of augmentative communication. It means that speech is not sufficient so we augment or add to whatever residual skills that they have, but if we were working with a, let's say your family and they decided that it wasn't working and they didn't help me let's say as an example and they went to the next person. What can I do? How could I stop that as a strategy? How could I see the non-verbal signs? How could I sense? How could we open up that communication so that I could say wait a minute this isn't working, let's re-direct cause sometimes you have to try you know it's a trial and error sometimes, but then

I think the important thing is during therapy to consistently maintain asking them questions and have them doing see if their feeling comfortable in what they are doing. Like I said they may not tell you what they feel. This might be uncomfortable for them or this might be confusing to them and they won't tell you.

And maybe pre-explain what your doing. you know maybe say I'm doing this and the child to speak better. I'm doing this, then maybe you can explain and things like that. Explain what your doing

I think with Asian community you probably will need to spend more time to do family counseling before and after therapy. Actually make them become involved in the environment so cause a lot of families think that this is like a lost hope and like it's use the term ah frustrated that we're desperate. They think this is the professional, finally found somebody that can help them, but they didn't realize that therapy take a while for the therapist as well as the patient do get used to the machine or technology or even therapy technique. So you need to get them involved and get them educated.

MH So if I were to ask a family is this working, would they tell me? Would they tell me?

Depends on

how comfortable they are

Yeah, it depends on the level of trust I think

Also you've like a diagnostic test is being test periodically and show them the improvement or any changes during different periods. I think that one thing is to make the family aware that therapy process is long term. It is not something, not a quick fix program, so they don't have to expectations. Something that will see a result quick, but something that they have to work at. It will take time to see a change.

They have a lot of expectations

right
MH So it sounds like your saying as much information as one can provide that's a better use of the families time. They'd like a lot of information.

Not just verbal offering, but writing

MH So test results or projects or activities or number of symbols or whatever

Maybe if you have a translator with you while you explaining cause that will make you feel comfortable too for a while. Not just all the time, but often.

MH That's the purpose of this grant is to try and train bilingual/bicultural clinicians and then start to build on that. Then as we all work together cause our team is very different, everybody's different, but we have a main perspective that life experiences as possible and we sit around and we look at video tapes. We deal with cases and say, well I wouldn't do it that way and somebody else may say we'll I don't see that at all and so we have this constant dialogue saying oh, okay I hadn't looked at it that way or thought of it. That's kinda the purpose.

I think that the attitude of the Asian community is that we haven't been included in any kind of mainstream you know professional services so it's kinda hard to bring them out and get used to having this kind of attention. I think that the community wants to feel comfortable and secure that it's going to be an on going thing. It's not some kind of experimental, you know we've got enough data and ah thanks, but you know thank for service but no we're not going to continue.

MH Okay we've talked about your perceptions of decision making with professionals. We've talked about perception of technology. We've talked about perception and experiences with disabilities and those are really the issues that I wanted to kinda learn from and I've learned a lot and I'm also very aware of everyone's time so that I don't just keep you here all day and talk to you and ask a lot of questions, especially since it's around lunch hour and everybody's getting hungry, but I have one last question and that is I also want to be very careful that I never stereotype. I never profile. I never make assumptions that people I mean everybody's an individual certainly, but because we have this particular composite here um there are two last questions that I would like to ask and one is are there subtle or great differences between the different groups that we have represented. So is there anything that's particularly representative more of the Chinese culture that would be very different from the Korean culture perspective or Vietnamese and so forth.

Can you give a more

MH Let's talk within the three questions- disability. Would families care for, react to, treat a person with a severe disability in a similar way in the Korean home verses Chinese homes verses Vietnamese do you think? What are your experiences?

I don't know about the question, cause we don't know the other culture
We can say how we feel about our culture

Then you can make the comparison

MH The reason that I'm asking you is as you listen to each other today. Do you hear things that sound the same? Do you hear things that would be different? Ah

I hear the difference in our perception of treatment. How we treat people with disability as a family because like my father said about the cousin. She always, she was always part of our life, everyday. I play with her because we were about the same age. Always I call her cousin with the family ?spec? whether she's disabled or not. Like we'd eat together. I'd feed her just like an older cousin which needs that. We talk about her as she part of our lives and then after she passed away I still have questions about her, but I would, I would feel like my aunt or uncle they don't talk anymore. I didn't even know how she passed tonight. I woke up she disappeared. I ask around everybody what happened. They don't really say until my mom told me like privately oh last night this happened and that's that. That was about that.

I would like to say that it's universal. I mean expectations. I mean the ah the appearance of miracles. That's universal. I wonder if it's possible or practical to um give the family who needs some help a schedule say of your performance and to build up their confidence of you. You can prove the improvement or function of your treatment or service or what not. If it's possible to do that. That would be a good help to, help in building up their confidence and ah and build up their patience and that I think that you have to let them know that everything takes time and patience. That's the very important thing to do I would think so, despite origin.

MH Any other comments or issues or questions that you have for me? Last parting work that you'd like to share with the world of professionals in speech language pathology regarding disability, use of technology?

If I can put in my two cents.

MH Sure go for it

I feel that Asian community is still like I said has been pushed back for many years. It's not like that we don't actively seek for help it's that the services are never made available or information is not readily made available for us. So I would like to see some professional who really wants to help the Asian community and can actively go to their mass media and start from there and create a grapevine effect so to make no matter you know people from there for three generations. Or those who just migrate to this land to know that there are services and do not be afraid that people with knowledge and patience to work with you. They are really there to help you, not to just make you a number of statistical formula.

I just wanted to say also another source that you might want to hook into is maybe talk to the doctors in the community. I think that when I working as a pharmaceutical rep in Little Saigon I was able to cultivate a relationship with them and talk to them about the need and I think a lot of times Asian doctors probably don't even know our service as a speech therapist for their patients.

That way the doctor communicate the patients and the patients will feel like oh that doctor know him. I trust that doctor so I'll go to the therapist.

MH That's a great idea. The reason that this grant was funded in California is to meet a shortage and there aren't enough persons trained in this new field that I call augmentative communication cause it's only 10 years old. There's only about 700 persons in the whole country with this area of specialty in addition to that's one shortage, in addition as you know there are so few people trained as speech language pathologist to work with persons from cultures other than Euro American cultures. That's another big shortage. We just don't have enough and that's why we got the grant. That's why we're able to help students here um go to school and have their education in order to meet those two areas of shortages so exactly the kinds of suggestions that your having and certainly those of you who are in the program post bac or undergrad coming up through we're kinda waiting for you as long as the funding continues. It's looks like we have about three years left to continue the work with students and funds. These are the kinds of dialogues that we have constantly to try to develop strategies that are appropriate therapies and offer an expanded clinic here in house and do it better, work with families that are unique and offer those kinds of strategies. I really appreciate you taking you time today to share this I know that it's a little bit uncomfortable the formality of being video taped and audio taped, but clearly there were many good ideas and strategies that Greta of someone will start to write all this down

As long as I get paid

MH Yeah, and build on it so I really, really appreciate it. I particularly appreciate your offering and heard that as your daughters here working with us more and more and as we reach out and um modify our practice, the pictures, the communication boards, sign language, a lot of it is real narrow in terms of what's been developed and we want to broaden that and make it useful for other persons and we need information before we can do that so I really appreciate getting to know you and um spending time with your daughter and I might ask you to help me translate.

Whenever you need it???????

MH Thank you very much. We're really proud of our training program and as you can see we just got great students and they teach me probably more than I teach them. I come to school everyday and I'm overwhelmed with

here to learn

MH I think that learning is life long. I just always stay in school and sit around and keep busy.

Focus Group with Hispanic Families with AAC Devices

June 19, 1996

Mary Blake Huer, Ph.D., C.C.C., Moderator
California State University-Fullerton

Summary Background Information

Type of Group: Focus group of Hispanic family members; families of AAC users who are Mexican Americans; some are device users, one family is waiting for a device (3 women, two of whom were sisters)

Date Conducted: 6/19/96

Where Conducted: Carl Harvey Elementary School in Santa Ana, CA in the SLP therapy room

Logistical: The moderator had to secure permission from the school district. She wrote a letter which was submitted to the head of SLP who submitted it to the school cabinet for permission. This process took approximately four months. We were the only request approved during the school year. This is a school site which we use for student teaching each semester. The attendance was greater than expected. Everyone came. They took off work for the day to come. They brought their children with them. They more or less came on time, give or take 30 minutes. We had Mexican pastries, fruit, melons, drinks and so forth. We sent fruit, pastries and drinks home with each family. The entire session had to be translated including the consent forms word by word. It took us from 9 till 4:00 pm to conduct two groups.

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Synthesis Statements

1. Independence in home and community
   - Child attempts to speak daily
   - Family and others are encouraging child's independence

- 15th birthday celebration is opportunity to demonstrate personal independence
- Family communicate mortality of family members that child relies on
- Can communicate toileting and other basic needs

2. Communication with others
    - Family understand child's communication efforts, but others have difficulty
    - Child uses aac device to communicate with relatives
    - Child uses english on aac device
    - Child may question erroneous use of aac when responses should be self-evident to communication partner

3. Satisfaction with professionals
    - Professionals have committed themselves to teaching child how to use device
    - Child is happy regarding services provided by school
    - Children are able to detect levels of caring and commitment by professionals

4. Sibling concerns
    - AAC device may inhibit child's use of oral speech
    - Siblings took sign language, but had limited ability to use signs

5. AAC and the home
    - Family not concerned about damage that might occur
    - No benefit seen for aac usage in home by family- everyone understands child.

6. School/Family collaboration
    - Family feels that school included them in AAC decision-making
    - Family feels that agreement between professionals and family is critical

7. Acceptance of child with disability
    - Family finds strengths in love and goals for children

Transcript

MH Tell us a little bit about your son and what he does at school and just tell us a little bit about your son.

Everyday that he does need some help for the bathroom, that he can perform the functions himself, but she need to kinda check him. He can brush his teeth , but he needs to be checked and he can dry himself and he can dress himself with clothing that doesn't have any buttons.

MH· One more question, his speech, how do you communicate with him?

He communicates using his communication board or sometimes a little bit a sign language as well.

MH May I take this out? So this is an Alpha Talker and how long has he been using this?

One year

MH Can you tell me a little bit about your daughter?

She says that when she picks up objects they drop. That she has advanced quite a bit with therapy. She isn't able to walk. I guess with crutches. Oh, someone has to help her and she can walk a little bit when she has crutches or supports if someone kinda helps her along. She can go to the bathroom. She been trained to do that, but when she washes her hands. Okay, but she does need some help in the bathroom when she's because she might burn herself.

MH I see

Right now, they put some water in a bucket and she can put over herself. They are thinking of trying to get some type of adaptation so she can kinda be in the bathtub, right? You can tell me Julian if I'm having any difficulty following.

MH I was going to say Julian, if there's in addition that you want to add or hear feel free to share that.

And so they are trying to thing of how they can adapt the bathroom so that she will be able to take a bath and wash her hair. She can dress herself, but slowly. She helps her was dishes at home. She makes her bed. She knows clothing, so she knows where to put everything, everyone's clothes. The mother works with sewing and she likes to have, her daughter likes to help her. So what she does is that she helps her separate out the pieces and so she works with her in the house and a lot of times she say give me a piece, give me two pieces or whatever cause she's always saying I wanta help. I wanta help. She is now starting to do more things my herself. Like she can go get herself a glass of water without any help and she can turn on the Television or listen to the music. There's a lot of things that she does at home.

MH The question I would have then is when she asks you and wants to do these things. How does she ask you? Does she speak? Does she use sign? Does she reach out her hand? How does your daughter talk to you?

She trying y to everyday, she's trying to speak to them and they have said no, don't use your signs just talk to us. You can talk and so each day she's trying to talk a little bit more and she knows many, many words. She saying that she's kinda demanding that she become a little bit more independent because sometimes if she approaches somebody that doesn't know her. She'll kinda hold on to them and say oh I can't do it, Oh I can't do it.

Oh, so she says sometimes she'll say I can't do it. I can't do it. They say, yes you can, yes you can. She'll go I can't and they won't do it, so then she'll have to do it on her own and she can't.

Oh, okay there's a custom on the 15th birthday there's a special celebration they call it the Quincancera and that you know you dance and it's like a coming out party and she wants, so the solution to this is they are saying yes you can walk. Yes, you can walk. So she since a few months ago has been to stand by herself and a little while a ago she took three steps all by herself.

She says she's a little bit hard, well a little bit tough with her because she thinks that it helps her to be more independent.

She's saying that she has an older sister.

Okay, so she wants Sara to do things for her and Sara says, that

Sara will do everything for her.

She says that she is always telling her the truth about what things like in the movies they say someone dies and then what happens and so that's a concern about you know what if she passes always what would happen. She say that when Sutter goes and leaves the home, she's gonna be with her all day and she's a little bit tougher with her. She's always telling her the truth.

What she is saying is that she is being very frank with her that she understands the concept of death and that she's told that someday she is going to be alone because you know her other relatives are going to go off and get married and or leave and so that's why she's saying you must you know move forward because you will one day be alone. You need to value yourself.

She says that she does try to use her words and she can um often get words out, whereas if she doesn't know you know if she can't say something and they don't understand it. She often bring the object and show it to them.

MH That um um what your saying is very interesting and um I wonder when you have these discussions with your daughter um if she can have discussions that are similar to those with her aunt for example.

She says, oh yes, she can communicate with her aunt. There are times that they share the care of her and she calls her, her mom. That she has two mothers and that there are times that she can't leave to take her to the doctor or something and that her aunt will take her to the doctor.

She saying that her sister, the aunt, has stronger character then she has and sometimes she tells her she's being a little bit too flexible and you know and so you know she is kinda stronger in thinking that she should be tough.

MH I want to make sure I'm appropriate here. I want to change the topic a little bit.

MH What you saying is so exciting and so fascinating and what I say to my students in my specialty is in communication, it's in speech and what we're interested in is when children are in wheelchairs and if they don't speak how they communicate with their mothers, with their aunts and with their relatives. So I really what to talk a lot today about how she communicates and how he communicates with strangers and other people cause that's what we're very worried about when she's alone and when children are not with their families if they are able to communicate.

She says, yes this is a problem because they teachers and the aids and the family can understand Roci, but it's difficult for other people to understand them.

MH So like what I do and what I teach is how to help other persons understand them. Like with speech, pictures or um device machines like this one and so we want to we want the children to be able to communicate with strangers and with other friends at school and with other cousins and children that they play with and so we're trying to learn more about communication and so that's what I want to talk a little bit about with you about today if we can.

MH And I'll switch back. I'll take turns and go back and forth if that's okay?

MH Let's start with this and if you feel comfortable um and maybe your son can share as well. What do you think about this?

It is very valuable for him

MH Can you tell me some stories about when he's used it and with whom and um maybe he can demonstrate some of the things he says.

They have, they put them in at school, but they also use them

Oh, So she says that when they go different places, they can put in another sheet and they can also record special messages, like when they go to visit, like when she was saying when they go to visit his uncle they can record hi, uncle Matt.

They put a small picture of his uncle Matt and other relatives on the board and they also have other things for if he wants to eat something or if he has to move himself in his chair.

MH So you like this? This has been helpful to you? Helpful to your family? Let me switch again here, um with your daughter other than speech have the teachers suggested anything else: sign language, pictures or anything like this with your daughter?

Oh, okay they gave her the special seat. In fact, they are in the process of getting a communication board for her, so that one of the reasons why she has a special seat. They are saying for example, that with a communication board she could go someplace and she could ask for things to communicate more effectively.

They don't know how it works yet, or anything at this point.

Okay they said they are going to show her how to use it.

So they said they are going to teach her, she said they are going to teach her and they are going to teach us first how to use it.

MH How does she feel about that? Is she excited, worried? How

She is very happy.

She is very happy, she's using it in the school. They given her a demonstration, or she's given a demonstration where she show that she knows how to use it.

Everything they teach her to learn she is very continent and happy with.

MH That's wonderful, we have two happy families here.

they laugh

MH But, sometimes families don't like these. It happens often. So what we would to have you tell us and my students and um if there is any problems with these that you worry about or think about um so we can make them better or help you more as you have these devices and use them. I'd like for you to talk a little bit about that and we'll start out, maybe we'll start with this is a sister, her sister. Maybe we'll start with her sister and see what she thinks is gonna happen with this.

Boy with Device ---I'd like to take a shower

She says that she thinks that it may be good in some ways, but she's a little bit concerned because she thinks that there will not be as much emphasis on speaking and it will not help her to speak more. She said, well it depends- various cases you know and each child is a little bit different.

MH Tell her that's usually the first question and the first worry that everybody has.

MH And the purpose is to just add to her speech, never to stop working on speech. We always hope to work on speech, but we just add to it.

MH And sometimes, these machines cost a lot of money and they're expensive and because they cost a lot of money sometimes families are afraid they're gonna break or get lost and so do you have those kinds of concerns?

No

MH And about when she gets this next year. Is that next year she will receive it?

They haven't told her when, right now they just have the special chair.

MH When she gets that soon or a little later um what changes, what changes in your home do you think will happen because of that? Do you think there will be any different, what will be different?

Okay she is saying that predominately they think it is going to help her outside of the home because right now they really do understand everything that she's saying. Everyone in the family seems to understand things.

She can look at it and right now she can't exactly say what she wants, but she can point to a picture or something like that or she can use signs.

She has some signs too that she uses. She also says to eat. water

So they try to speak face to face and they try to help like work with her like this so that she can speak better. They say that they sit right in front of her and they look at her and then they try to say it slowly so that she can repeat and a little bit, by bit she getting better.

MH Now I have another question. When the school made the recommendation to you, where you included? Did they ask you questions? Did you talk with the teachers or therapist or did they make the decision?

She said that yes she agreed to it because she thought it would help her communicate better outside of the home like with the store and in

She could ask for help you know with stranger with the communication board

MH She felt the school included her when they were trying to decide what to buy, what to recommend. Did she feel like she participated in the decisions?

Okay, they basically said that they would ask them you know um if this was the way to go or if this was okay. If they said yes, then they would do it and if they said no they wouldn't do it.

She said the teachers spend a great deal of hours with her everyday and they know her pretty well and she thinks that they do everything that is the best for her child.

MH Wonderful, cause sometimes parents feel left out and sometimes parents don't have that kind of talk with teachers.

She said that it's really important for the parents and the teachers to be in agreement. That the teachers also know a great deal about the child and that's a very important part for them to work together to move forward and help the child.

MH Tell her I would like for her to come and teach my students.

MH Cause I hope that my students always talk with the families to work together.

What she says it's really good to have that communication that the children who have problems, the students who have problems and also the parents with child with special needs. That it's really important to work together.

She had problems since birth. She used to cry and cry because of the diagnosis of the doctors. What's the future? Just right, they started doing after 12 days that she was born they started to do therapy with her. They gave her a caesarian. They didn't doctors, they wouldn't have doctors or possibilities in Mexico. They have to travel three to the doctor and three hours from the doctor. She was unconscious. She was shaking. She was having convulsions. They said that there wasn't anything else that they could do more to do than to do therapy. She was in Mexico at this time. They got a tablecloth. They were moving her.

Someone leaves the room

They had a number of sounds, bell and various other sounds like that. They would ring these different kinds of things to give her auditory stimulation so that she could hear. They gave her that therapy from 12 days. She could hardly ever sleep so every 15 minutes all day long, all night long. They had different colored capes. They were fabric strips with different colors. Ribbons, ribbons okay got it. They would kinda show the various ribbons. They'd shake the ribbons or the cloth strips and they'd ring the bell and they would do it from side to side for stimulation. She couldn't sit. They would kinda have to support the

Tape 1 side B

They gave her therapy to show her how to . Just about every hour of the day at home they would do this. They would move her arms and legs and this was how she began to sit. She had lots of salvia out of her mouth. She would start massaging her when she was having saliva drool. They would wash her. They would do massage. They would put alcohol, wash their hands and put alcohol on their fingers and then they massage around here. After that she didn't drool any more. She couldn't always learn everything, but she would love to learn everything she could to help her daughter.

MH If I can stop here. These stories your history, your experiences with your daughter are so important for us to hear and know. For my students to hear, so that when we work with families we understand how hard it is to have children that are different. It is very, very hard, as teachers and therapists we want to work with you more closely so that we can make it easier for you cause you have had it very hard.

She says yes, it been hard, but when you have love and you have a goal nothing is difficult no I mean tiresome. She says that when she can see her beginning to walk. When she can see her sit. When she can see her go to the bathroom she gives thanks to god and to this country that has helped her with her daughter.

MH I really appreciate you sharing that. I'm gonna stop just a little bit cause it looks like your daughter wants your attention and I don't want to take you away from your daughter. So when your daughter talks to you in just a little bit, I'm going to switch and know ask about her son and her experience. So that your daughter can be happy and not feel like your ignoring her because your talking to me. Then we'll switch back to you again.

MH Would the daughter like something to drink?

She says that she likes to come to school and she really wanted to come to school today and she told her no you can come tomorrow for a graduation. She going tomorrow's your graduation and your going to be very pretty.

MH She's getting tired

Tomorrow
yes

MH We won't go to much longer. I'd like to switch back to your family and you've had a year of experience with this device, with this machine whereas this family is just about to begin, you've had experience. One year later to share some stories or some frustration or his it broken or has it always worked or just tell me a little bit about the experience you've had with your son using this is your family or with friends or his friends.

They said that first to start to communicate with him they took some classes in sign language. Everyone took sign language classes. Okay, so there is a 14 year old and I think a 15 year old and a 17 year old- 18 okay. So many brothers and sisters. So they all took the classes to learn how to communicate in sign language. Her youngest child has limited, apparently there is one child who is younger who has limited vision and he has limited vision too.

MH I saw a hearing aid.

He has spasticity in his fingers, so he can't move his fingers very well. It was also therefore difficult for him to communicate with sign language. He know very well the movements of sign language, but. Oh, when she was starting to move her hands when she was describing things he was paying a lot of attention because they would look like sign language movements.

MH Oh, I see

She started to laugh. He kinda understand then that they weren't real signs. Those people who do not know sign language can communicate with him or he can communicate with him using this. Yeah, his sign language is limited to those who understand it and know it. With this devices he has been able to communicate much more effectively with people.

MH Is this Spanish and English or just English?

Oh, it's interesting she says you can do it in either language, but the teacher understands more or knows more English. So it's actually done in English.

MH I see. Does that- the fact that it's in English make it difficult at home or with his friends or your family?

Yeah, actually he understands more English too

MH Oh I see, I see

She saying that her husband and the other siblings understand English pretty well and she's actually taking English classes to practice her English. So English is the language that is pretty much spoken in the house.

MH I see. Did this meet any expectations that you had before you had the device before you had the device? Maybe you thought about what it would be and it does having the device is it the same that you thought it would be or are there differences or things you didn't expect?

Oh, he well because for example if you say what is your name just like that. He was kinda going why do I have to have this? But she knew. She says yes, but she understands how it is useful that you can point at something and say how are you.

MH Does he have any problems with the pointing or the pressure it takes to touch it?

No

MH Who picks the pictures that on it? Do you pick the pictures that are on there?

She does, she uses the sign language book. Okay, so they take the pictures from the sign language book and they put in them in because he knows those pictures from the sign language.

MH Are there others other than theses? Are there more pictures?

They have another page. Okay when they go to visit someone for example, his uncle they can record hi Tio. Hello uncle and um that's what they will do because he can do it with sign language, but his uncle and aunt don't understand it.

MH In your home has it changed the communication in you home, him having this versus before he had sign or this.

She feels more secure, more sure of herself. She says that actually it's made her a little, it's been helpful because before she would always have to check him and check him to see if he need to go to the bathroom, but now that he has this little button that he can push and say I need to go to the bathroom she doesn't have to worry.

MH So would she say that it made him a little bit more independent than he was before.

She says that also for example, when he has the couch at night he can punch the button that says I feel sick and she'll come running. They always leave the door open so they can hear. It's loud enough.

MH Sometimes families want their children to be more dependent and sometimes families to be more independent. So this has made him more independent and that sounds good you would say?

Right now he is more independent yeah.

MH Let me ask a couple of more questions. With both of you if you could teach me or if you could help me teach future students and therapists and teachers do you have any concerns, any wishes, any needs how the university trains students? How we could be more helpful to you in the future for communication? Do you have anything that you could tell us that we could learn and to be more helpful even in you future with your children?

It all depends on the condition of the child. Yeah, for example she can speak, but her son can not. He has spasticity in his vocal folds and so he can't speak. They are different cases she says.

MH It's been my experience that every case is different. I've never seen two cases that are just alike. They are always different, that's why it's very hard to train students, but we also want to be, we want to keep learning more and more so we get better at it. So that why I really appreciate you talking to us. We can be more helpful in the future.

Okay, she says that children who have special needs have a sense of who out there in the public cares about them or puts attention on them or doesn't reject them as opposed to those who do reject them. Even though they can not always communicate effectively, they can instinctively sense who's going to accept them or give them attention and who might care about them. And that's something that is extremely well developed in these children. She says also they can sense it when someone is trying to teach them that really cares about them, has a feeling for them as opposed to someone who is just showing them something and really doesn't pay attention to them otherwise.

MH Thank you very much. I think we care really going to stop.

She says that she is very grateful and thankful that you invited her and that these talks about children with special needs and your concern and caring about children with special needs and she's so very happy to be here.

MH I'm very happy your here too. Thank you very much.

Focus Group with Hispanic Families with/out AAC Devices

June 19, 1996

Mary Blake Huer, Ph.D., C.C.C., Moderator
California State University-Fullerton

Summary Background Information

Type of Group: Hispanic Family Members; Families of AAC users who are Mexican Americans; some are device users, one family is waiting for a device (two mothers and a husband/wife pair)

Date Conducted: 6/19/96

Where Conducted: Carl Harvey Elementary School in Santa Ana, CA in the SLP therapy room

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Synthesis Statements

1. Communication at Home
   - Family members typically understand child's communicative attempts.
   - Children often use nonverbal language at home.
   - Family may prefer use of speech at home to AAC device

2. Communication in Community
    - Child may prefer use of AAC device in community but not at home.
    - Children recognize that persons in community may not understand them even though family does.
    - Many families will recognize the importance of multiple communication modes for child.
    - Family may be sensitive to public displays of sympathy.

3. Need for Independence
    - Family feels importance of children understanding the need to be independent in some daily life activities.

4. AAC Desire Features
    - Family likes icons or desires.
    - Accent on device not be an issue for some children and families.

5. Working with Professionals.
    - Family is happy when professionals work on AAC usage in academic settings.
    - Families express needs to understand how to program devices.
    - Mothers and fathers may express differing opinions about professionals working in the home setting.
    - Families feel it is appropriate for professionals to be sensitive to intrusiveness of home-visits.
    - Professionals should support children's use of AAC devices and not criticize or reject children.
    - Families appreciate the efforts of professionals.
    - Families want classes that teach them to help their children.
    - Families want everyone to work together,

6. Coping with Child with Disability.
    - Children understand their parent's frustrations.
    - Family feels it must help child even when they don't understand child's communicative efforts.
    - Some families may feel child would be better off if death had occurred shortly after birth.
    - Families want others to care about their children.

Transcript

MH You might also tell them that we've worked with the manufacturers that make the communication machines and we interviewed and asked them questions about working with persons to help persons communicate as well. So I noticed you mentioned other group, you might also say we included the group of the business, the manufactures as well.

MH Then also this afternoon we are going to interview the teachers and therapists and video tape them and ask them questions as well.

MH You might ask if there is any questions that they have before we get started.

She saying the children do not need to be here.

MH No

He says that he does not exactly understand what questions to ask because you are going to be asking the questions and so he's just listening.

MH So let's get started. Well try to go about 30 minutes or 40 minutes of question and then well turn everything off. There is no wrong or right answer. We're just wanting to collect information and we want to get the families opinions and experiences and their concerns.

MH I would like to know a little bit about them. I'm not sure who is here and if they are a family member or.

Two families- the husband and the wife. Mrs. Lopez and ??Viva?? Lobos Family

MH I would like to start out my asking a little bit about your children. The focus of today is to talk about how your children communicate with you in their family, but if I could just know a little bit about your children because I haven't met them. How old they are?

MH This afternoon we'll kinda take turns and go back and forth, but if you have anything that you think about and you would like to add certainly jump in and feel free to comment and um participate.

MH So let's start. Tell me a little bit about your child.

9 Do you want all the ages?

MH Yeah that would be

Let's see 24 33. The names no, but the ages?

MH Yeah, that's fine
Okay 24, 33, 34, 35, 30, 28, 25 Alex 13 Michael 10 and 7.

MH And the child that comes here to this school and works with these therapists is

Michael- 10 years

MH Ten years old and um tell me a little bit more about Michael is it that is 10 years old?

He doesn't walk and he doesn't talk. He likes sports.

(I think someone else walked in.)

He goes by both Miguel or Michael. He likes sports. He goes to the park. He can play baseball if they help him hold the bat. He has a walker. He loves sports. He says he really, really likes sports. He thinks he knows more about sports than dad does and he likes to go to the park and you know he just very interested in sports. Sometimes they use, she knows more about the language of signs, so what she'll do very often is ask him questions. Do you want to go to the park and he'll shake his head yes or no. Or do you want to go the store and he'll shake his head yes or no. Sometimes he has problems because he has I don't know what his diagnosis is but he says he holds himself like this so it's difficult, but he does have good movement with his fingers. So at times he could press a button or touch something and um to do that. He uses that at night especially. What he does is that there is a poster in his room at night and if he needs to call them what he can do is he used to hit it with his whole hand and now he hits it with a finger and that will it speaks. Then he can call his parents.

MH I see, let's kinda move around and have a brief description of the other children. So I have a sense of the type of communication and machines or signs so I kinda see. I'm kinda blind.

28 years. He is here. She said at first he could just say sounds like yes you know he had trouble with yes/no -various sounds, but know he can say he want to go take a bath. He want to go to the bathroom. He want to eat. So he can say a lot of things verbally now. He didn't like being at home. He doesn't like to be at home. He like to be at the park. He likes to be out on the street. He likes to be in the store. Every time he goes there, he wants music, music, music.

MH So he's ambulatory?

It's a wheelchair.

MH So he's in a wheelchair. He's 28?

Oh, no she's 28. He's 10.

MH He's 10. I'm just trying to have a sense of their experiences and their children.

Up until about 6 or 7 months ago he could just say one word, but now he's able to say more. He can call everyone including his aunt and uncle by name now.

MH We're going to come back because I want to see how that was accomplished.

He says he speaks to her in Spanish and he speaks to everybody else in the house in English.

MH Interesting

Okay there are some things that he's saying you figured out a lot of it, but like water and such. He used to say those. Now he says a lot more things in Spanish and English. What she's saying is that everyone in the household can understand him.

MH Thank you. I'm going to switch now.

She says she's 33 years of age and she has two children, a boy and a girl. He is 9 years old. _____ is her son who is here. He doesn't speak very well, but he understands everything. He understands English and Spanish. He seems to prefer English or at least he says more English. He does understand everything in Spanish the thing is he just has a small vocabulary in Spanish. Bato is one of his uncles and he's got mama, papa, water you know etc. What she is saying is that even though he can't speak very much he can show her things with signs. He might make-he'll give her a sign like he wants to eat or drink. She'll say do you want to eat or drink. He'll say yes or no and so that's she seems to understand him very well using that system. They understand him very well. Some of this you have already picked up, but she says on Saturdays and Sundays he doesn't really like to stay home. He wants to go tot he park or he wants to do Chunk E. Cheese, or he wants to go Super Nintendo or he wants to go out and play with his cousins. He likes to use the communication board. He likes to use the computer as well. He likes to use the computer, he likes to use it. At first he didn't know how to write many words, but now he knows how to write many words and he's a very smart child.

MH So

Actually he prefers to stay in the house on Saturdays. So you know if his cousins live a far distance away, but if they come you know if they are gong out and doing something he wants to go with them. When he went to Chunk E. Cheese, they had the little horses and she put him on the horse and helped him hold on and he really liked that.

MH So what I would like to ask with the families. I want to focus specifically on how the three children communicate. All the things they do, except speech. I'd like to have you talk about everything they do so they can talk to you or their family except speech. I want to get the sense if we use communication boards or machines or sign. So if people could just speak briefly about everything for communication except the speech, I can get a sense of

He speaks very little at home. For example, when he's very okay also what she is saying is when he is doing his homework and he needs some kind of help on his homework he'll show her using signs. He won't use words. So one of the things is that for example if she wants for him to put if he wants for her to put him on the carpet he'll show her by signs and if he wants his toys to be closer to him he'll show her by signs.

MH So it sounds like predominately, the communication is sign for her child?

He only pretty much uses sign. Sometimes if there's a thin toy or something he can grab, he will grab it. If he can't reach a toy I think he'll make signs. Okay,

MH Okay we'll just keep kinda going around here. Michael his predominate

Yeah, excuse me. He says that he sometimes can say some words like the name of the Maria. You described it as being inside of his mouth, um he can say yes and no. He will kinda babble sometimes, like if he's in the middle of a movie or if a movie is being put on and he doesn't like or if it's not at the right thing or if he doesn't like it. He'll kinda babble especially to his mother and she'll rewind it or she'll take it out and he does have some movies that he really tends to prefer and ones that he doesn't. You can almost tell by his behavior which one he likes and which one he doesn't.

MH Does he use any form of communication other than speech.

So he does use some other modes of communication. For example, if they want him to go outside or to the park he can show by his eyes. His gesture of his eyes, like he demonstrated that he wants to go someplace and he knows everywhere that they go and so for example if he takes him the wrong direction he'll start kicking and moving himself around because he doesn't want to go there and that's a way he signals to his family as to where he wants to go. For example, he has toys on the rug and he'll try and roll to get closer to the toys and he'll get them.

MH Thank you, I think your son used sign, if that correct?

No he doesn't not at all. He says things better now. She said they used to use sign, but now they tell him you've got to tell us. You've got to tell us and he will.

MH I would like to explain a little more. The area that I teach works with a lot of machines or sign and because of that and because we are interested in that I would like to get the families opinions of machines that speak or communication boards with pictures. I would like your honest opinion if you like them, if you don't like them. I very interested in what you, what your perception is of machines, if you've been exposed to that and anyone can.

She says that she really doesn't use the machine particularly because she depends on the speech. Linda brought the device twice to her house to show her about it and you know she prefers to say talk to me, talk to me.

MH I want to ask you some more questions

Oh she likes the device at school, but not at home, not in her house.
He saying that he does like the device and that's because even though they understand him in the home when he goes ousted they will not understand him. What he's saying is that he thinks that as children get older they have to be more independent and that it's really important that she will ask, his wife will ask questions and she will find out what he wants. He use signs of some kind to communicate with her, but when he goes out there, there is no one out there who's gonna ask him questions and that he is seeing older children with communication boards and where all they have to do is touch it and then it will make I have to go tot he bathroom or whatever and can communicate well and seeing one as 50 different boxes.

There's a little difference of opinion here. It's very respectful because he was saying yeah and what she said was that her son used to be like Michael and that he used to have more difficulty communicating. For example, if he needed to go to the bathroom, he would move around until she said what do you have to do and he would say bathroom, but now that he can speak more effectively , speaking wise it's enough for home, but it's fine to have it at school and um and that's fine with her, but they are different cases. Actually, he was saying that he was trying to agree with her yeah, but my case is different.

MH I would like to um be real clear to say that I don't have any preferences for whether you like the machines or don't or like sign or don't. My role is to train students to be professionals that can be really helpful to families and so my role is to talk to families so much that you tell me and I learn from you how I can be more helpful. So if you don't like the machines that's okay, but I need to know then how I can help your child when they're not with you the mom, but with strangers or at school and so if it's not a machine then what is it? How can we be better? That's the whole purpose of me training and asking questions and I respect your honestly and your willingness to share your feeling so much you can't believe it because I don't want to do something that's not useful. That waste my time and your time and so that's the purpose and if you have difference of opinion that's great. I love differences of opinions.

She says that she really believes of modes of interacting. That it's important that he learns how to use the communication board at school and that but it's also very important that she gets him to speak at home. She gets him to talk, so that he has those two modes of communicating. IF you can image if he could speak completely and wouldn't need the board that would be much better.

MH What worries me is if your not with him and he's with all the other people in the world except for you. What's he gonna do? That's what I worry about in terms of making sure that he has not two systems, but one strong system with all the other communication that he needs as well as at home.

For this reason she wants to show him how to speak. She says that in the last 6 months that he's learn to speak much, much more. He listens to the radio. He repeats the words, also he is repeating things on television and really paying attention to the words and he sings. He doesn't like to play with toys now. Right now, he doesn't like toys. He likes to be with older children. He likes to be listening to music in the garden or being with his older friends.

He saying that he very convivial. He's very interested in other people. He likes to go and see sports. He likes to be with other people. That a lot of them will come up and say how are you? How are you doing Michael?

MH His son?

This is his son Michael or Miguel. Oh, I was basically saying yeah, we get going and just kinda keep going. What he's basically saying is that yes, yes, he does what him to learn to speak. He does try to speak. He does try to share things, but he is very concerned that when he goes out. Out on his own, when he's out on his own that it's very important that he be able to communicate with other people. He really thinks that communication board is really gonna make a difference. He understand everything. He understands everything. He know when other people don't like him. He's very sensitive and he also knows when someone else is rejecting him.

What she says is that there is this whole thing about when he was younger, she didn't think that he would ever be able to go to the bathroom by himself, but little bit by little bit he was able to do it. It's just the same thing with speech, it's like this idea of trying to speak and keeping on working on it a little bit, evolving, evolving, and evolving. She says that you really make a difference. You kinda put it in their mind of yes you can do it. You can do it.

MH Thank you

She likes him both places. It much easier. She would like him to develop his speech as well. She would really like him to pronounce words, but it's like no you know it's really difficult for him to do it. The first words that he learned are the bad words. It seems like the good it's not gonna happen, but the bad words.

She said yes that's true they learn. What happened was it really bothers him if people say poor little guy, poor little guy and poor little guy. One day he was outside and someone did the poor little boy and he just said stupid. He said bitch. I don't need to translate that. A lot of bad words. He knows how to give the finger. He says I don't care. I don't care.

Oh, sometimes they say what happened to this child? What is wrong with him, but in here and in this school they never say that. Sometimes people don't want to look at him so they turn their head so they won't see him. He says that sort of stuff really bothers his son. He doesn't like it when they say that poor little boy. He said that it really bugs him because sometimes people will come up and ask what happened to him? Why can't he walk? It really makes him upset.

One time there were people surrounding him saying why can't he walk or whatever and he just went bam and hit him in the face. He was upset. He was a child.

MH I want to pose another question now that we're all relaxed and talking. Sometimes the manufacture's come to our campus and talk to us about these machines and um our students we look at them and we ask families to look at them. I would like for you to tell me what you think about the pictures that are on the machines and the voices that come out of the machines and the colors of the machines. Have you seen any devices, machines? Can you speak to that a little bit?

She likes them. They are very good. She does too. They are very good. They like them.

MH Some of my students have said they don't like the voices. They think the voice sound like Euro Americans. They don't have an accent. They don't speak Spanish. They don't speak Chinese. They don't like the voices. Do you like?

She says this is okay. They learn English also and have Spanish in the classroom.

He likes it. He likes the colors. He likes the photographs. She used it with a little head device. So he has a small television in his bedroom, but he prefers to look at the big television in the living room. Okay, sometimes he indicates that he wants to go on the rug with his book. He started to babble as if he were going to say something, but they don't understand him.

MH Now if it's okay I would to change topic again.

MH I'd like to talk know about the services you've received from he school and if your uncomfortable we can ask the therapist to leave or they can stay. I would like to know what you think of the kind of therapy that your children have received for communication for speech. I want to talk about the good aspects of speech of it and anything that you think that had not been so good that maybe we could have other ideas to improve it.

MH Do they want people to leave or do they feel comfortable?

She says basically she's worked with Linda for 7 years and she's done all sorts of things with her on the communication board. He has learned to add, to do figure. Learn things about the neighborhood and all sorts of things. Also work with him on talking and everything she does is just great. They work together, for example, they're working on colors. So Linda will work on colors on the communication board and she's work on colors at home. Numbers, Letters everything.

MH Is there anything that she wished she could do in addition to that. Any other suggestions?

Okay right now they are working on mathematics

MH So right now, pretty happy?

satisfied

MH No concern?

No, problems. So they have a very good, that we talk a lot. We communicate and we work on things together.

MH Cause what I like to teach my students is to always ask the parents if there is anything more that they could do.

He says that they've also just like _____. They've been in the program about the same time and they are working on the same things: mathematics and various other things. With a touch that he can add things together and it's been very, very valuable. He says is that he would like to learn how to program it. The school works on programming and Linda works on programming and he thinks that they could probably learn how to program it and that would be really helpful in terms of helping him become more independent.

Okay, he said many, many things. One of the things that he said was that many times that Linda has offered to come to the house to demonstrate things for the family. He has always kinda felt you know if would be after school and he felt that it would be a problem. Not that it would be a problem, but it might be an imposition on her and so he has always said no, no don't come and he didn't know that she had been working with Mrs. Lopez in her house. So everyday he comes in and brings Miguel and takes him home and so that you know that might be a possibility. But he was basically concerned that he wanted to be considerate of Linda because he felt that might be you know just asking too much.

She says also when you come to the meetings you can also talk about it and say things like that.

MH I guess because I'm watching the time here in terms of your children and everything and we have some papers and other things to have you fill out. The last question that I would ask is what would you suggest for me as a teacher to say to my students before they go out and work with families?

First of all have a lot of patience. She says that you know that if they try to help the student and it like support they will like that, but if you know if you like reject them or criticize them. They will just shut down and go like this and they won't say anything. They are very bright. They are very bright.

He first of all said that it is wonderful that you are concerned about the welfare of these children. That he is so grateful that everyone is here and that the speech language pathologist are concerned about their welfare. He says not everyone is concerned about their welfare. He said as parents we can work on their behavior. We help them to be good people, but we really need the help of the specialist. He is so happy that we're there to help and she suggested that perhaps maybe they could have classes to teach the parents to use the devices and to work with their children.

MH That's something that we could do at the university on a Saturday. That's something that we could do.

What they are saying is that really important to have that union or working together with the teachers, with the speech language pathologist and with the parents. That they can really accomplish and she says yes, you can accomplish a great deal when you all work together.
MH For our training program where we have 30 students. It would be wonderful for the students to work with the families, so they could learn and learn much more from the families and from the teacher to before they go out to these professions. That would be a wonderful idea.

She saying that she had a lot of suggestions and they just kinda gone. She says you know that whenever she goes to a meeting and she's got a lot of things upstairs.

What he is saying is that it is difficult because both of these ladies are now by themselves with their children and that it is very difficult.

She has two and she has one and that it's difficult.

I'm saying what suggestions can be done to help you as a single mom or?

It's very clear that... She says that you definitely need the help. How can we help children with their communication. She is saying that it is difficult. It is very difficult. She is not resigned. When she says that she feels said or she's crying, they know, they know and so it's very difficult that way.

They understand every move. They understand. If you can not understand it, then you can not accept it, but we have to help them. We have to help them.

It's almost like it would have be better if, for it would have almost been better if he had died. If he died, yeah that's tough. Oh, he almost died. There was like 72 hours where they didn't know if he would live or not. So what had happened was that they because he was you know because he lived. They said she has done everything she could to help move him forward. She says you have to do everything. (Mother is crying) She said that because this is my son, I'm going to help him go forward. She says I feel this way about communication. I'm going to help my son communicate. I'm going to help him talk. They said that when she had Michael, they said just leave him here. Don't take him to the house. They told her that he was maybe gonna live a year, but not for very long. He said he would only live one year. She said thanks to god. What happened was that they said that if she took him home, he would have to be fed by tube. That he wouldn't be able to breath and with help she breast fed him and the doctor told her that when she left the hospital congratulations.

She said I'm going to go forward and yes I am alone, but I am going to go forward and he was saying what compassion he felt for these mothers having these children and being told that they would not live for very long and that you know the pain that they have had to go through.

MH I want to interject here. What is the right word. I am very happy that you would share you stories with us and allow us to vide tape you story because I think to train professionals they have to hear the stories. They have to hear the stories, so they can be more helpful. What we are trying to do at Fullerton is to be able to link with families more. To listen to your stories and to help you with at least the little piece of communication which we can do. Sometimes it is nice to have a time to share openly like we have this afternoon because it is very difficult, very difficult everyday. We certainly appreciate that and this is the part that I think that I think student often need to be aware of.

He's saying that he's very happy that this could possibility help some other people. Maybe it will make them care more, maybe it will make them more effective.

MH Our number one rule is that if the therapist and students don't have a heart we don't want them to enter into the profession.

They have to understand they have to feel what has happened.

MH I think at this point I think that we should, maybe we should be a little more

Her situations different because she didn't know that he had a handicap until he was six months old.

They said that in both of these cases that he was going to be a vegetable. He said instead of giving them strength or hope, what could they do? It just brought them right down.

She said how disheartening it is to go in and see that they are going to put the tubes in your baby. It is very painful. She didn't have that problem.

First of all she said that when it came time to feed the baby. They said no you can not feed the baby because we are going to do it by tube and he said that he didn't want to say anything against doctor, but then, but when he felt that the feeding tube that went in may have damaged his vocal folds, his sons vocal folds. He said that sometimes they would put in the feeding tube and sometimes it would come out bloody.

Okay, she kinda helped the nurse who was very sympathetic and helped her to feed him by bottle.

They said in some ways it's actually a blessing because their child understands. Their child has can understand and feel what's going on and for example a child that is blind. They can't see and there's other difficulties. Before her son she really didn't understand about pain that much or you know or sadness and she's learned a lot.

They know everything. They know when there's money. When there's no money.

He says, he was saying that sometimes he look at her as if why are you sad or whatever and then she'll tell him why and he'll think about it and that it um that she can see it happening and you can't say stupid things in front of him because he understands it all.

MH Well, I want to thank all of you. I think that the time is getting a little bit late and we want you to sign some papers so that you can get your money. We want you to eat some food.

Focus Group with Related Services Personnel Serving Predominately Hispanic/Latino Populations

June 19, 1996

Mary Blake Huer, Ph.D., C.C.C., Moderator
California State University-Fullerton

Summary Background Information

Type of Group: Hispanic Related Service Group

Number of Persons Present and Roles: SLPS in school district serving Hispanic children and families: two SLPS -Barbara Mouness and Linda Perez (bi-lingual); Dr. Terry Saenz, a faculty member at California State University-Fullerton was also in attendance

Date Conducted: 6/19/96

Where Conducted: Carl Harvey Elementary School in Santa Ana, CA in the SLP therapy room.

Logistical Issues: We secured permission from the school district (see above). We were very tired as we had videotaped all day with Hispanic families.

Modifications Required in Protocol: None. Participants were asked to complete all paperwork. Because of the long day they chose to complete only some of it as it was late and they did not have time. No other special circumstances.

Synthesis Statements

1. Expectations for AAC
    - Hispanic families will be grateful for help from professionals
    - Child will be able to talk immediately at home

2. Expectation after Receipt of AAC
    - Frustration
    - Concerns regarding damage
    - Devices programmed in English at school, but family uses Spanish at home
    - Families want recommendations on programming
    - May understand child's nonverbal language and fail to see value of AAC at home
    - Families of young children may not want to use AAC at home

- Communication issues may not be a family priority at home
- Family may not have time to invest in a/c at home
- Learning to use complex device may be overwhelming

3. Professional Concerns Regarding Hispanic Families
   - Many professionals will want AAC devices programmed in Spanish and English
   - Use culturally sensitive strategies for training
   - High caseload of professionals may limit training capabilities
   - If children are convinced of AAC importance, families may be more accepting
   - Families have many questions regarding AAC usage
   - Families will use AAC devices inappropriately without necessary supports
   - Use Spanish text and videotapes for training
   - Professionals may need to visit home setting repeatedly to ensure implementation
   - Training must be seen as being useful to families
   - Teachers may emphasize academics for AAC usage while families will have other concerns

4. Professional Perceptions of Families
   - Nonverbal behavior is important to families
   - Families will love their children despite degree of physical involvement
   - Hispanics are event- rather than future-oriented
   - Families may nuture dependence in child while professionals may desire greater independence
   - Families may have unrealistic goals for speech in their children
   - Families should emphasize total communication
   - Hispanic famlies differ from euro american families regarding acceptance of child's disability
   - Sibling responsibilities differ between hispanic and euro culture
   - Siblings may assume responsibilities for programming devices

5. Device features
   - Families may have concerns regarding overlays and cultural appropriateness
   - Families may find simplest devices too complex

6. Families and training
   - Though vendors are getting more input from families, training is still professional-oriented
   - More time is needed to train families

7. Families and team meetings
   - IEP meetings afford little time for families to share feelings
   - Families may not have time to commit to meetings

8. Use of support groups
    - Families may benefit from use of support groups
    - Enable professionals to train families from the beginning

9. Working with families
    - Some families will prefer professional contact at school vs. Home
    - AAC is dynamic s; sometimes devices won't work
    - Professional should acknowledge when devices aren't working and more on
    - Public relations skills are important - not taught in preservice programs
    - Don't generalize about Hispanic families- must recognize individual difference

Transcript

MH The first questions is regarding expectations that you as professionals see families have and your expectations for families. So if we start with the family first, what do you think that families expect from AAC devices and don't get, if you had to answer that from your experience? It can be from any of the families that you've worked with you don't have to just limited it or you could just divide different ethnic groups if you want to do that. What are the expectations that families have when you say okay here's a device. It's been delivered. You've got it. We're gonna work with your child. What are the expectations and anyone can start.

I think that um the different cultures it is a different expectation. I think that the Hispanic culture is looking at it as whatever you can do to help my child, whether they're gonna help them talk. Whatever you can do I'm really pleased with it. Where maybe another culture might say that we really want it to work and it's just like you know we will follow through at home. We want to have major say in what's going to be put on it and how it works and what device we get. I think that there is a difference in that way.

Yeah, I think my families have been really enthusiastic about learning about the device and hearing that the child has been using it in the classroom for academics or maybe for calendar time, for circle time in the beginning- the calendar. Things like that, they are really excited about it and their enthusiasm gets me excited. I think what they expect when it comes home is that the child is going to be able to talk like everyone else. The frustration begins when there are some limitations to that device or it might be complicated. The usage of it and the setup of it.

MH That's my next question. After they get the device are those expectation met or do you see changes or kinda what happens?

I think they are. I think there's a lot of fear of oh this is such an expensive device that if I take it home I have all these other kids at home if it breaks what am I going to do. The responsibility of that and trying to make them comfortable is important. Having input on what they could say on it. Another thing being, it has to be in Spanish, maybe at school it can be in English, but they don't understand the English at home. It's really hard with some of the devices because there, it's not digitized speech. It's synthesized and that's really hard to get into Spanish you know. Also you ask somebody what does you son or daughter have to communicate and it's like I don't know. Then you start thinking of things or you know or pulling it out of them and then you see all of that. Most of them really want you to give them the ideas on what to put on there.

MH Let me continue along that line and bring Terry in a little bit while you guys are relaxing here. It's hard. I think the first time I filmed I was like this and now it's like we've done it enough. The purpose of this grant is to really focus on the technology. It's an assistive technology kind of grant. The whole focus is to really look at these devices. I wish it would have been a little bit broader and we're making it broader by adding culture, but we'll kinda follow this. As far as AAC, the devices the question is does AAC positively impact families and if so, how? I'm going to start with Terry first, because Terry has really had limited experience with augmentative, but through me she's learning more and more about augmentative and I'm learning more and more about culture as we work together as a team. So we'll start with Terry because if she listens to you she will know the answer. So how do you think AAC in particular the part of AAC the devices impacts families?

I think that it could potentially from the perspective of the family. It could have a positive or negative perspective because um I think a family that really sets it's goal communication and in anyway academic performance and what's to be actively involved in that is probably going to say this is a great thing. I really want to do. I think in some families where there's the perspective that um there's a lot of other demands. Say there's a very large family. There's concern of things being broken. There's a sense of that they kinda always had a sense of what the child is communicating and if they feel that kinda of a barrier or that's not necessary. I think that the family may view it as not necessarily a needed or positive thing. I'm just looking from the family perspective, what I would project it to be, not what we believe as professionals or what is potentially possible.

MH What about you guys? Positive or Negative?

I think I'm finding out that the younger that you get the kids and are able to work with the families, the little more accepting they are. If you start with them when they are in junior high or maybe even 12 or 13, it's like well I understand him pretty well in his gestures, his eye movements, whatever he needs cause they've had all that experience with him. If you start at a early age, the early intervention I think even if it's not necessarily a device, even if it's just a picture board or some kind of different communication system including sign. They might be a little bit more accepted. They might accepted it a little bit more because maybe they've been experiencing it all the time. As they're older, it's like okay this is good for school, but I understand him just fine at home. Plus they have a whole lot of other worries, sometimes I go to the home and instead of doing the training I wanted to do I listen to maybe they're getting ready to get evicted or somebody just lost their job or how am I going to feed all these kids you know. They don't really want to hear what I have to say on training and how to use it. You do run into that.

MH Linda?

I think again, families are really enthusiastic in the beginning. They are really feeling like this talker that I, and that's what we call it many times is talker at school is doing so much for my child. I want to see what it can do in my home. I want him to use it. I want her to use it. Yet, when it gets home, many of those things that take place in the home: feeding, bathing, taking care of other family members, one parent coming home from work and it exhausted and the other parent is going to work in the mist of the child coming home on the bus. Just all the things that need to be done for that child in the evening and then is a concern and is time concerning. So that the device many times doesn't get used, um in addition to that when I have been in the home and helped them out with training, with learning the devices. They are overwhelmed by the complexity of it. They will even say to me you know I don't get it. Many times I will type it up on the computer, how in English the steps: step, step 2, step 3 on a card that I have right there in Spanish and in English. Still it is very difficult for them and I respect that cause it's sometimes some of the technology is not easy for me and I admit that it's difficult to learn some of that technology. It's difficult for them. It really is.

MH I think um and I'm going to send a message to you Julie for just a minute. Other series of question ask about a relationship between family members, level of independence that an aid gives, times management issues, but I think people all over the country will talk about that and it will be similar. What I would really like to do is jump do because you guys deal with the population that's so unique and probably in other parts of the country they don't have the experience you guys have. So Julie I'm going to jump down to questions and that is what is the greatest concern, and Terry you can jump in on this one as well, have encountered in working with families with AAC decisions. You can speak to that and you might look at it from a cultural perspective as far as working with Hispanic families when trying to make AAC decision in terms of practices. So if you can kinda just shed light on your experiences, especially in dealing with the Hispanic culture I think that would be valuable.

It probably wouldn't, I don't know if I can sum it up in one concern, but I think

MH Well list, you can list. That's why I jumped

Some of my biggest concerns is what Barbara mentioned earlier is the fact that I want to have those devices in Spanish. I want them to go home in Spanish, so that they could chat. Yes, it does take putting the device when you have a very physically involved child, it does take putting the device on the chair and getting it ready for the part or whatever cause many times the weekends are filled with parties in their families, so the child can communicate. I want it in Spanish and in English because in classroom they are going to usually be doing everything in

English. Those academic skills and many times my students have incredible abilities in the academic areas. I want them to succeed in English with the maximum of academics programmed into the device. So that's a concern for me. Training, is a concern for me. Training my parents in a way that is culturally relevant to them, to where they can try some things. Maybe learning to take small steps with them. One area would be just trying homework. Doing a couple of pieces of homework with the device and bringing it back. There a concern of how much training and in what steps to take with that. In addition to that the amount of time with very large case loads and the physically involved students not being the only students on my caseload. We have caseloads between 60 and 80 sometimes a 100 students on the caseload and wanting to give the amount of time that student needs to meet with success. You feel like your dabbling sometimes you know. You feel like there's just is not enough time to make it successful and um so it's hard to really sum it up in one concern I think.

I found that if I can convince the student that he likes it or it's helpful. They are the ones that can really work with their own family and say you know this is really good. You know look what I can do. So I work a lot with um as far as the assessment part I include the family and tell them what we are doing and what we are looking as and that there are various devices out there that do various things and how do they feel about that. Would they like us to continue? Most of the time they say absolutely do that and so then I work with the teacher and the aids or other people that are working with him and then if they get pretty proficient in it or even if they think it is fun and start to own it themselves. Then we talk about letting it go home and then you really have to have the family and the training just for nothing else the battery. Frequently it will come, yeah they're really good at bring it back to school, but the battery is dead or they didn't you know they turned it on but it didn't work. How do we fix this? How do we fix that? How do we get from one theme to anther and then the training and then a lot of times you go to their home and for me I don't speak Spanish so I'm going through an interpreter. I don't know if what she is telling them is correct or not you know. It's like

It's hard to stay away from those technical terms

That's right and if they don't understand the making of it or what's going on, Then they're just repeating what you say and they really isn't understanding or comprehension. One of the ideas, how you had mentioned you had it in writing and stuff in Spanish. I think just from the video tape, maybe video taping going through and programming or just not the whole thing, but just the major things like turning it on. How you fix the switch. Where it's supposed to be, if they use one. How do they go from one theme to another. I work with them going over it and over it and you can't leave it. You need the time to go back, at least once a month because even if I learned a device and maybe spent two or three days on it and I thought I really knew it a month later it's gone if I haven't worked with it. I have my book out and everything else. Well, what do they expect to do, the book isn't in Spanish.

The key, I think the key is making it useful to them. Is it going to meet their needs, if it does not meet their needs they have no use for it. I respect that.

It just gets in the way

MH I do too.

That is where there have been times when I have been frustrated and thought come on you guys I know you can do this and then I had to take a step back and say hey it's not meeting their needs. How am I gonna make it meet their needs? That's why I thought through in little steps. Okay, maybe just homework, because the teacher is saying that homework is coming back and it's being done by the student. It's being done by the parent. I don't want this to happen. I want that student to show me that he or she can do that homework. So there is a need there possibly you know that would do it. Okay, maybe like the one student wants to talk to all of his family members on the phone, but he's finding some barriers. Then that would be my goals and that's it. He uses it to talk on the phone and nothing more. So that they really see this is purposeful. This makes the difference in my child's life and in my life because he can talk on the phone know and that's what he wants more that anything else.

I just to and again this is a theoretical level. The thing that I would wonder would be a question probably implicitly in a lot of the parents. The idea of when the child is through the educational program how is he or she going to communicate. It's like where does everyone on the assessment and the team that works with this child. Where's that child gonna be? Is that child gonna be continuing education? Is that child gonna be at home? Is there gonna be a communicative device there? Do the parents, and I'm thinking again we're looking at a cultural difference and we know the data tends to say that the Latino cultures tend to be more non-verbal. So there's a lot of maybe a greater sensitivity to non-verbal communication. When the parents were talking about all the little signals that the children were giving them and how the child seemed to have a sick sense and how in tuned they were into that non-verbal communication. Part of that could be, well they're just know their child, but part of that could also be you've got a cultural sensitivity that non-verbal is just as important. So you got less of the expensive of we've got make it explicit. We've gotta put it on board. Then you've got parent's who are saying; where is this child gonna be when the child's out of the program? Is this child every gonna use this device again or not? Or is the child still gonna be a full fledged member of the family no matter what? One of the greatest things that I've always admired about the culturally diverse individuals who were Mexican and American-Mexican was the love that they have for these children. We could see it here today. They love that they cared about that no matter what they really loved those children. For many of those parents, it doesn't matter how involved that child is they will always love and nurture that child. That, they may feel that's sufficient.

I think that is hard for some of out parents to look at because we as educators. I think that is another of our concerns that I didn't mention. Is that where is student going to be as an adult? If we don't start now, we've lost too much time. They get to high school, and then you try and start them with a device, sure they might be able to learn some things, but how much could they learn if we could start early. So we don't want to lose any time and we're all enthusiastic and we're pumping forward. The parent in the Hispanic culture as far as and you can correct me if I'm wrong, is much more event orientated. So today, if my child is happy and content and goes home clean and dry and things like that, then that is what is important to me. That event is important to me and their future is something that they don't tend to worry about as much and what I've heard in IEPs is when we bring up that question is where will your child be in the future? They many times say don't worry about that. We have that taken care of and if they're elderly parents they say don't worry about it. We've already got it taken care of.

MH We've heard that echoed in the Asian group as well. It is a real different orientation and that brings us to another one of these questions and that is: do you think values and beliefs of families are different from your own? Then the next follow up is, if it is what do we do about that? You know when you have a set of values and beliefs and as a professional I mean it is almost how do you see your role? Do you put those values and beliefs on the family or do you accept their values and beliefs? I think that is some of what we're talking about too, let's start first with have you met families with different values and beliefs from your own and if you did can you think of an example and kinda talk through what you did with regard to assistive technology.

First, I tried to convince them that this was the best thing for their child no matter what. This is just, once this child gets this device. It is gonna open this whole new world for them and they are going to be able to communicate with their family and this and that and it's like the parent is usually like is well they are thinking a lot of times I communicate with my child just fine. They get very protective. What are you saying? You know and I see a progression where instead of moving that child toward independence or being as independent as they can be. They would rather nurture them or cuddled them or just keep them safe, real safe. They are treated real differently than the rest of the children in the house. I've seen children where they had their little responsibilities and stuff. You can always tell the child that is treated like everyone else or the one that's cuddled and you know just caught up in that. They want to protect them because they feel sorry for them for whatever reason. I think that is different. I would rather see children move to be as independent as possible. I'm not sure that the Hispanic culture does that. They want to take care of them and it's like where do you want to see them? Do you want to see them have a job? Do what? It's like, um don't worry about it. They will always be with me or a member of the family. No, I don't see them in a group home. No, I don't see them holding a job. It's okay. So getting past that I want to say, but don't you see that they could be so much better if they didn't do that. That's my beliefs

I'm not saying anything. I'm not saying anything.

See that's my belief and I'm blaming that on them and sometimes you have to step back and say well are you going to react to that or it's like I know what's best for you and that's not always true. I mean it's never true really, but yet they respect you as a professional. They appreciate everything you do. They know you are trying to help their child, so it's like you kinda have to step back look at what your own beliefs are.

MH I think that on the grant that's what's been most interesting in terms of I fell like I'm collecting without any judgement or preference. I'm just collecting and then I have an array that I can kinda formulate and think about against my own beliefs and values and against other beliefs and values I've learned about, but it's like collecting. Linda, do you have a story or experience?

Yes, definitely. I think my value systems have been very different from the values of some of the parents. I think my values have included that individual becoming as independent as possible. I've seen individuals grow at this school from, I haven't seen them actually go through it. I haven't worked that long, but some have been here from 18 months to 22 years of age. So you've seen their independence grow, you've seen kids learn how to be independent within this school and take on all of their personal care and get their needs met. I've seen them learn to ride a bus system and go from here to South Coast Plaza and purchase what they want and then get back on by themselves. I've seen them get into jobs and be able to use their communication device within their job, do the best of their ability. So you've seen all that independence and you think this child at this age they can do this. I've seen it happen and yet that may not be the goal of their families. I think my example would be sitting today and listening, to one of the parents speak of her son. To speak of Mrs. Lope, talking about Sergio and how much she wanted him to talk. I've heard say that before, but I just thought she didn't understand me. She just didn't understand the capabilities of the device. She understands perfectly, but she wants her son to talk. Now from my point of view as a specialist in looking at his oral motor structure at the point that I got him. It was so involved, I never saw him as an oral child. I never saw him as a verbal, as someone who would be verbal. So my expertise would say don't go in that direction. Yes, make him functional, as functional in his feeding and in his chewing at a very young age. I do remember him here at 3 years of age. I would work on that, but I wouldn't go into the speech areas other than yes and no. From mom's enthusiasm and her passion for him to speak, I think if I were more sensitive to that a couple of years ago when I first got Sergio I would have put that on the IEP and I would have pushed for that more and um I can't think of the word. I would have defended that. I can't think of the right word. Defended that

MH Advocated

That type of therapy along with augmentative much more now that I hear her speak so passionately and very respectfully. I was very impressed with how she expressed herself, not feeling like she needed to be defensive towards the communication device, but she could speak very objectively about that and yet very passionately about verbalization from Sergio. I think I would have gone much more verbal and thank god he's developed it with mom's push because it probably didn't come to much from the school because he doesn't verbalize as much at school.

She accepted if it wasn't real clear as long as she understood what he was referring to that was okay. That is what she wanted. Oh, yeah I might understand you because I know the referent or a teacher might understand you, but are they going to be functional out in the community. You know a lot of parents I want them to talk. give them a chance. Give them a chance to talk and it's like why not? You know I try not to totally not do one and not do the other. Whatever is gonna work. Whole total communication- if it's gonna be pictures or if they'd rather use some gestures and signs, use a device, verbalize. Even though you almost look at these poor kids, some of them poor kids I'm saying that again and I know they don't like it now. They struggle, they struggle so hard to talk and to be clear and it's frustrating and that's why you think well I've got the perfect thing for you. You know something that's gonna talk for you.

I think we get, again with high case load we get in out therapy mode. I have put most of my kids that are on augmentative, I've given them an hour of my time a week. I couldn't get everything set up in a half hour, but still I've got that hour and I'm going to get accomplished what I'm going to get accomplished and the verbalization w. Forget the verbalization. Yeah, yeah, I understand you. Let's go back to your device.

But we're responding to it too.

I'm pushing. I'm constantly pushing the use of that device. I've even got the aids to do that now. Tell me on your device. I don't understand. Tell me on your device you know. Your not really trying to understand his speech and to respect that.

MH Because this is a focus group I can't comment to much. Other than to say that I think that we live in probably the very best place in the country and just the kinds of things your learning and seeing just from letting everyone be themselves whatever their style is, whatever their experience is it's really nice to just kinda look at and learn and say huh and change and grow and so um that's what's been most rewarding about these groups. For everyone to just state their opinion and there's not judgement and there's no well I just.. and so with that now I'll let Terry state her opinion

Why am I chasing at the bit too much?

MH No, but

Gosh what did we say?

No, no not that, I just what I find is that

MH She'll come from a very different culture perspective

I always do

MH If you cold be with the four of us as colleagues and that's where the richness comes in, so you'll see that just as you listen to the families today and to each other and whatever Dr. . It's just kinda interesting to watch how people perceive the very same phenomenon from their own perspective and so with students what I think is very important if we all could just add two more to our repertoire every year then we'll have a broader collection of styles to use to fit whatever the case may be to use an augmentative term a bit. So

It's funny I look at this from a professional and as a person too because my spouse is Latino from a traditional Mexican American family and so I see sometimes implicitly. I'll read books about culture that get at a deeper level and I'll sit there and compare. There are so often just passive sorts of beliefs. Independence is good, that's a very Euro American belief. That's not necessarily another cultural belief and the idea that one should achieve and one's judged by achievements that's another thing that's very Euro American. It's interesting because I haven't worked so much with this particular population, but I have worked with a variety of severely handicapped children and what I've found is that these operational license sells in different ways. That for example, I could almost always count on my Latino parents to that child would always have a home with them. That child would always be loved. I would be amazed at how they would work daily self care skills into the routine or give the child. The child might flip tortillas on the stove you know and this was a pretty involved child, but the child had a place. The child might sweep the floor. The child was a full member of the family. In contrast, I would see a lot of Euro American parents being very concerned about what's gonna happen next and always counting on them to move the child forward, but I also saw a lot of rejection. That child would be judged by how well he or she achieved. That there was always that sense. That tremendous grief about that child. That perfect child who was lost. You see that with these parents, too you really do and I think it was interesting just I think in a cultural context. I think in a lot of Mexican American parents are very devout and you hear again and again the sense of going back to with god's help for with whatever. There's that context. I've had colleagues of mine talk about Catholicism as kinda an acceptance about god's in charge. So I think that there's this sense, I wouldn't call it resignation at all, but this sense of accepting what can't be helped and adapting gracefully to it and also considering this child in and of his or herself is of value and so I try to I see my own biases coming out sometimes. I see my own cultural thing about I want kids to be independent and I want them to do this and that, but I can also see I have a tremendous I think affection and appreciation of this culture. I think that there's some things that they do very, very right, that my own culture doesn't do as well or consistently and I always look, usually when we compare these cultures we're looking at lower income, less educated individuals that are Mexican American in many cases when we're looking at the Spanish speaking population which has immigrated from Mexico compared to middle class much more educated um high income, can offer more things and more options and more independent Euro American families and in some respects I would say that those Mexican parents chalk up very favorably in certain respects. So I would love to combine both cultures and get the most out of both and it's almost like for me though you have to start at that culture as the starting point. Like you said, you said something very powerful Linda about starting with um what is important and significant to that child. What is needed in that home to make it functional for them because once they've decided that's important for that child. Relatives, I'm wondering how can you apply with relatives cause every single parent that came in here talked about doing things with tiro or tia, aunt and uncle. Putting things on the communication board.

Siblings as well

Yes

Sibling, sometimes I find that um cause the siblings usually if they're older speak English if they've been here a while and so I've done a lot of training with some of them. They get into it. It's like I'm really doing something and there not quite as busy as mom and dad. So a lot of times they take over deciding what's gonna be on there. What's needed, actually helping them use it. There's always a sense of family.

There's that cultural role about siblings take care of each others. Now, again I'm afraid that I'm going off into generalities and it's never okay to say all people of any culture like such and such a way, but again that really valuable. So again the way you train is gonna be different because you've got siblings who are going up and taking more responsibility then their Euro American counterparts.

I didn't have that in school.

No one does. No one does.

MH That's why this is kinda an infusion of culture and AAC is still a little baby and you put culture which isn't very old either together and it makes a powerful subject. Let me go to something here that I think is particularly relevant for you guys to think about and that is with regard to AAC devices, specific devices and kinda think about any experiences you've had. What things about the devices, so you could think of overlays, or symbolic representation or access or memory or color tend not to be considered by family members? So think about especially Hispanic Latino if we were looking at those devices what things, what aspect of those tend not to be considered by family members in your experience?

Not considered?
MH Not considered

Unimportant

MH Not utilized or not relevant or not important, but something that is not considered whereas we as professionals may put a lot of emphasis on that. So it the particular component of a device. What thing, things not a very good word, about ACC devices tend to be considered by families in your experience.

Other that color, to tell you the truth I never asked them what color they wanted. You know I might have asked the student was color important.

MH You mentioned batteries

batteries, yes

MH Just think of practicalities about devices.

Having to take care of it. What do I do if it doesn't work. Remembering to do the batteries. I think part of that. I think it's not important, it's just that they get so busy that maybe that's the least important thing in their day. Instead of feeding the family when they come home and making sure, but some families are really good at it. As far as overlays, that's really important. They really care about if it's in Spanish and if it's the right voice. If it's a boy. A boy's voice. If it's a girl you know may the right age. My voice is a lot of girls. It's like well I don't sound like a Spanish speaking person either, but sometimes times constrictions. If you try to do something fast you just do it. A lot of times the kids don't care. They are excited that they can just talk. As far as anything else and you know

I haven't had my families be concerned or consider any of it as far as the color or the voice or anything. I've had other people say to me, oh that's the same voice as Lisa. I thought that was Lisa when I heard that, whereas the families don't really think about that. Again, the time consuming part with some of my devices that are, the Alpha Talker that's much like a tape recorder a. I've wanted to tape record young boys voices in it for a boy user, but that's time consuming to bring a child out of the classroom and do that. I though it would be much fast and that's time consuming. Some of them have my voice in it. Partly when we've done something really fast and my husband's voice in it. So he'll have a man's voice. The parents have never said anything to me. Sometimes it's time consuming to do that, but what I don't think if your asking the question what they don't consider is the complexity. The simplest device is really complex. It really is.

But I almost don't think that, that's just the families, because I've found working with teachers. Anybody I train, it's like it's speech therapist. It's gone. they call you on the phone and you know I can usually walk them through it, but it's like I don't want to deal with this.

Yeah, it's just too much time to handle
It's too much and it's like well this is a really user friendly device.

This one is really easy, believe me.

They go yeah, yeah, yeah, right.

They try it and then they'll call me and say what did I do wrong? There's just a little button here that just wasn't pushed. Dad, Mr. Grielobos has come in to me many times, weekly and said I broke it this time. I know I broke it this time. It was just that it wasn't in single switch. It was in head pointer or um keyboard. Instead of single switch for Michael, so he couldn't use it. Even the teachers will switch.

Even the teacher will do the same thing. They'll call you and say it's just not working. You go over well, just push this button.

To us it may be simple, but to them it's very complex.

MH I think the manufacture's sit and create little strategies in the little module. They should probably should immerse themselves with families when they are doing their creative thinking.

I think, aren't they working towards that style. I mean they are taking input from parents and professionals. You know because we're seeing the communication devices becoming more user friendly, more easier for families. They are some, maybe all of the colors. There really wasn't color before. Real voices as opposed to no real voice. You know I think they are trying, but

MH I think though if you look at the training, that my experience has been they still want tot rain professionals. They don't train consumers. If you look at the trade shows you don't see them spending time at the booth with the families. You see them with the professionals.

That's to whom they sell usually.

MH We're doing a lot of reflection

Most of our families can't afford to go to the conference.

MH We're dong a lot of reaction papers, where we just do around and watch and my note of that. Let's see a couple more questions, if you had a wish list, this is Huer's version of these questions. If you had a wish list and you made a list of items about what changes you would make during the decision making process to make it easier to work with the families this could go both direction now. What would you list to make it easier to work with the families for AAC? So what would you take away or add to? If you look at decision making for assistive devices.

More time, more time to train them. More time to be sensitive to their needs. More time, more time bottom line and working with anybody. I find other professionals, like if the teacher is really gun hoe on this device that can be really helpful, because they know the parents a lot better than we do. As speech therapist, we might see the kid every other week or something a couple of days, but they are with them on a daily basis. If they have a good rapport with the parents, then I tap into that and I go and involved the teacher in anything to do with the family because I know that's strong. Otherwise, it's really tough. How do you get closer? Other than going to the home as opposed to having them here. They feel more comfortable at home, sometimes they don't. Sometimes I think they are a little embarrassed. You go to some of the homes and it might not be white middle class American home. There are just as uptight as you are. How do you get past that? I heard more parents say stuff today that I've heard a whole lot of , except I do fine at home. I can understand them, but I'm really happy with what your doing. Keep doing it. I'm really pleased. I don't know.

I think a lot of that had to do with open ended questions and the freedom of time. I think our IEP meetings are regimented and there are so many of them a year that they're regimented and time constraints on them and this is to tell you what goals have been met and what goals need to be met for next year and that's it. There's very little time for the parent's to share what they are feeling in those meetings and they have the opportunity to do that.

Sometimes, they do even, they don't have the time either. It's like is this gonna take long? You know because they have to pick up their kids at another school. It can only be at this time, I have to be home to receive my child or I'm one my way to work or I'm on my lunch break. So I hear a lot of that.

I haven't heard that as much

MH I was amazed, amazed that as many parents came forward and spent so much time with us today. I was very aware of their time commitments. I would watch if they were glancing at their watch or looking at their children and that they took good time to come in and spend a few hours with us. So I expected few persons to come and actually follow through with the commitment. So would you like to speak to why might

Pressured them into here's what we want to hear you say. I didn't even except for they were gonna talk to you about using AAC or a device. You as a Spanish speaking person. Say what you want to say.

I think that the three parents that came from this school are just very committed parents.

MH Was that the morning group?

No the afternoon group. The afternoon group are just very committed.

MH Then the earlier group came from a different school.

From Barbara

They are from various schools. One is from Jefferson. One is from Sal a Back. One is a high school student. One is getting ready to go into junior high. So they are kinda out there. I think sense the SH population a lot of it is moving out into the district, instead of into the enclosed safe group. Some of the parents, I don't know, I think they are glad that the kids are being included, but I think they feel a sense of loss too of the community. That real strong community, but they're you know these parent you know that's probably because the were really, they would be willing to come and give the time to do that too.

MH It's a wonderful asset to both of you that they came. They didn't know me certainly. they might have know Terry, but it was just wonderful. They just came and stayed and I'm just amazed.

They do what needs to be done for their children. They're very busy people.

MH They were honest and open.

Each one of them. Mrs. Lopez, the mom and let's see now, she's working from early afternoon to late at night. Mr. Velobos has other children here that are his grandchildren I believe. His grandchildren that are going to school here now, because he has adult children and so he is back and forth you know picking up kids and everything. Mrs. Redos is working as well and taking classes in English. They are very busy people, but very committed to their children.

MH It was just wonderful that they took the time and made the time to share with us. I really appreciate that .

I thought something to respond to your question about what might be needed or useful. I saw something really intriguing in the afternoon. I think this was based on what I was hearing Mr. Velobos, where he had said I did not want to impose on Linda outside of her normal school day, for her to come and demonstrate things to me in my home. I just did not want to do it. I did not want to bother her. Yet Mrs. Lopez over here had been saying oh, well she's come out twice. She's shown me this. It was kinda like he was reconsidering and rethinking. I'm wondering that I saw such an incredible dynamic among the parents. Now all these parents are the same school. They've talked to each other. Their kids know each other and now I wondering if there's times were it's real appropriate to have a group of parents. A group o parent who support each other and working on the same thing and they share. Now again, I don't have 90 kids on my caseload, so this is anything that anybody has to do, but that might be very, very powerful. We are looking at a culture that has been described as collectivist. That's not individualistic each. Each person does his or her own thing, but automatically moves toward community with other people. Automatically those ties are so important and again that's an over generalization, but I saw. You see people really working together and really seeing that as supportive. That might be powerful.

That's interesting that you bring that up because I think as speech language pathologist and also kinda immersed in special education for a few years. We're pretty comfortable with family interviews and with what their needs are and individually if we feel comfortable with the language we'll go into the home and sit down one on one and talk to them. That might be very helpful, but it might be interesting to have a group of parents sitting together and talking about what are your needs in the home, because then one opinion stimulate someone else's opinion. They can really talk about what their needs are and um take a very active role in this because once you start something that is very time consuming as a augmentative communication device, very time consuming for a speech language pathologist to learn the device if it has a sophistication to it. Then to teach that or train that to a parent. To have their active involvement from the beginning, might really help them to see that they are a part.

To have support parents because they were automatically lining up support for each other in their conversation here and I would probably feel that way towards each other, but you could just see how someone who's further, who's been more successful could really, really share that with others and be and all it takes is a couple of parents who are leaders to say wow this is really the way that I want to go.

I think that it's easier like with Linda's kids because they are in the same school. When you've got kids all in and this is a big district, very big district that might be the only child on that campus using a communication device. Actually they love it because it makes them look special and everybody comes up to them, but the parent support they're gonna come all the way over some place else. A lot them know Carl Harby if their kids are in a wheelchair because they come here for therapy and stuff. Something like that would be really good, but it would tough to get them together at the same

very tough

Especially with all their kids. What do their do with their five other little kids running around. At MITCHA when we've had parent conference or parent groups and we do that a lot. We provide babysitting in another room so that the parents don't have to be watching this one running here and running there. Sometimes they are more comfortable then talking. They always come. A lot of them come believe it or not. As long as it's at a good time. It's not in the middle of the evening, sometime during the day where they don't' need a babysitter. They can catch the bus and their not out at night. All those things are considerations and sometimes a lot of the parents don't want you to come to their house. I've had that, where they would prefer to come to school.

I think one of my, if it's okay to just express. One of my changing philosophies of augmentative is it's not something where there is an end all. That I have assess this child and that's it. This devices is the best for them. I'm gonna make them use it or else. It's not like that anymore. My philosophy is changing and from the moment that I come in contact with this student until the moment that they leave to go somewhere else it's a process of assessment. I really feel that if we were and I think it's a really interesting idea to get parent together that if that was tried and it didn't work then so what we tried something and it didn't work because I really feel if can benefit at all we might go from a parent meeting that we thought we were going to have once a month forever to three strategic planning meeting before your ready to implement some device or something like that. I don't know, how it would happen, but I'm much more in favor of looking at it as a process and if that Liberator no matter how much energy you put into it with that student if that does not meet their needs in a certain length of time you can let it go.

It's real hard to let it go.

It will be okay because it's a process. It's a process because you go from the thing is that something to really consider that we have had our eyes open to is the way the laws are changing now. That child for the most part changes every year, so think about that. That means your training a different teacher every year because we want that child to be in the regular education classroom

Then your starting to think about what is the right classroom for this child?

We used to have three years, four years.

Then your getting into placement issue that really aren't any of your business, but they are. Is this teacher going to promote using a communication device or is it gonna sit on the shelf. That happens, so we end up working with the one's we know are gonna promote it. Well that's not individualized, I mean what about the poor kid that could use it, but your not working I mean all you can do is try. You know it's really frustrating to see it sitting on the shelf.

MH It gets very complex, increasingly more complex I think every year.

I have had like you know a parent well she wasn't too sure go and talk to another parent that had not as a group. I had them meet in my office and it's like this in my office. It's like well I thought maybe you could get together and tell her what your son or daughter is doing and do you like the device. Now I don't know if she was saying what I wanted to hear or if she was really being honest. You know that's hard to tell. You try to be as okay whatever you say.

MH Well, I am just amazed at you two. I mean I do a lot of augmentative I mean that's what I do, but I think you guys are just hot. So we are gonna work with you and have a lot of students here and hope to develop more a of colleagueship as we reach out because I think what both of you have done and what you've built and what you have and what you know and your experiences and your willingness and openness to be flexible and say I tried and it didn't work or by god I'm gonna try.

It's hard. That happened to me this and it just, I tried so hard and finally it was like I was sitting with the teacher just like alright this isn't gonna work and its like okay.

MH A lot of human relationships and dynamics as it is.

It's all PR

In our rigid ASHA accredited program they don't teach us in that class. We don't know about counseling. We do a little bit now, but human relationships, intercultural communication now all of the inclusion and all of the stuff that's happening in schools that I don't even know about that I haven't kept up on. It's amazing that we all don't have nervous breakdowns probably.

I came close last year

MH from the stress

I find myself working more with adult and people working with that child then the child. That's frustrating to me. It's like when did I lose that? When did I lose that one on one contact. I set it up and then I work with parents, the teachers a lot, the aid, and I feel I've lost touch sometimes with the kids.

MH We all have very different roles. In the repertoire again and it's what people expect of us. We bring that role. Well speaking of my role I promised you we wouldn't go very long. We gone over that, but I'm gonna start wrapping it up, but we have a comment from my colleague.

I'm just realizing that because this may get national distribution, probably will national distribution and dissemination I kinda have to put in my thing about I think that it's real important when we talk about the people that we saw speak today. we talk about our experiences we are looking at first of all we are looking at Mexican American culture and you know we can't really generalize it across to other Latino cultures very freely here. Secondly, I think we are looking at there's a lot of individual differences in every culture. There are some general trends, but and so you have to be very careful generalizing and we're also looking with fairly, I would say probably most of our parents were moderate to maybe a little on the low income side in an urban area. So it would be terrible to say all Latino parents are like this or even all Mexican American parents are like this or your experience as a person who is participating is going to be just the same, but it's a good way to maybe provide some hear say. Some things that may come up and they happen across the country and here's some things, ways that people that deal with them. These two ladies had so finely have delineated and this is a path to understanding, but I'm just really afraid. You have to very careful that we don't say this is the way it is and this is how we're gonna expect this and my goodness let's start up a whole new set of stereotypes.

MH I think that we've made that very clear

I think we have

MH in our willingness to work this gentlemen. His name is Dr. Phil Parette in Missouri. That we expect to participate in the review of the materials before they would ever be released because we are such advocates for our families and I would be very angry if anyone individual member were used as a stereotypical model and so we have a lot of trust and respect on all the parties that this will be used in the right way to provide examples and increase understanding, never to hurt anyone or stereotype or any of that. So I appreciate you saying that Terry.

That's our disclaimer.

MH The one group of the Latino population because we don't want to mislead the public, however these segments are put together and we hope to be very active in terms of reviewing and no or yes. Participating in that process as well.
I think you work in San Anna, you don't even think about that because most of the population is

mostly Hispanic and if you enjoy working in this district you just kinda. When I put a student on an AAC device I don't think about, you know maybe I should because then your looking at the other culture a little bit differently, but it's like um that just we're so used to working with this population. It depends on the kids.

MH It does make a difference. If your in Missouri where this team is they have a 12% diversity and Southeast Missouri is the home of Rush Limbaugh. When I went back there to be trained as a focus group leader. Another women and I we kinda did a double take cause it is a very different culture and Dr. Parette has learned so much since he has done this grant, just as I have. So it's kinda interesting, but we always want to remind them to be very careful.

You not only experts in your own right, but your also in a district that, who's mission is very, very clearly I know Shelia Leevy your the coordinator of the communicatively handicapped program is just. I know that when I place students in this district that all of you have been so well educated that I always have good placement and that anybody in this district basically who's a speech language pathologist is going to be sensitive to these issues. So it's really a delight.

I think Sana Anna is ahead of a lot of districts.

Oh yes

In anything that they do and they do and if something happens new, like augmentative communication. I thought all of the districts were doing it, well they're not. They don't have any body that's trained and this district has allowed us to spend the extra time doing it. I know I should be doing it full time. It's a full time job, but they are at least allowing me three days, which is more than half time to devote totally to it. That's a lot of district aren't' getting it, so I know I'm really, this is a progressive district in all areas.

We thank Sana Anna and we talk Shelia Leevy and we talk both of you. What a day. We will call this Julie in Missouri another rap from Cal State Fullerton.

Structured Interview With Navaho Family

February 15, 1996

Sheila Stuart, Ph.D., C.C.C.
New Mexico State University

Summary Background Information

Type of Group: Structured Interview with Navaho Family who Uses AAC; conducted by Dr. Sheela S New Mexico State University

Date Conducted: 2/15/96

Where Conducted: Navaho reservation, Fruitland, New Mexico, in a module unit used as a library at Ojo Amarillo Elementary School.

Number of Persons Present and Roles: Janice Mailman, Navaho mother of Desiree Mailman; **Desire Mailman**, 11-year-old female who has used an AAC device about three years

Logistical Issues: Desiree required some direction in the initial part of the meeting. She seemed to want t control the "camera" focus but was diverted and settled into allowing her mother to visit with the focus gr facilitator.

Modifications Required in Protocol: None

Synthesis Statements

1. Uncomfortable Use by Mom
   - Mom spends most of the time with her
   - Mom says she doesn't really know how to use
   - Mom recognized she needs skills to program
   - Mom has fear of programming-afraid she will erase things

2. AAC Device Aids Quality of Life (QOL)
   - Helps her to communicate
   - Helps to understand her needs
   - Emphasis of communication is on social/emotional issues
   - Quality of life enhanced by using more sophisticated device
   - Uses device to talk with grandparents

3. Limited Use of Device at Home
   - User upset when siblings play with device
   - Siblings need to learn how to use
   - Device left at school so siblings won't bother it
   - User uses low tech for communication at home
   - Hinders communication with family

4. Importance of Training
   - Especially for mothers
   - Siblings need training
   - In culture with extended family training for aunts/uncles/grandparents
   - Information on device comes primarily through school

5. Maintenance/Use
   - Mom assumes daily maintenance without seeing as burden
   - No problem with space issues in home
   - Uses symbols that come with it

6. Family Needs/Concerns
   - Would like some Navaho language
   - Navaho needs to help user have a role in her clan
   - Portability of device difficult when traveling

Transcript

SS: Des can you introduce yourself

DM: NO

SS: How old are you Desiree?

DM: 11

SS: Your 11 years old. How old have you used augmentative and alternative communication? Remember how many years?

MM: How long did you use this?

SS: Or even the one before it?

MM: Do you remember?

DM: NO

SS: Okay, mom can you tell me how long?

MM: About three years.

SS: The basic thing that we're trying to do with doing this research is to get a feel for people who have used it and to find out what kinds of things are "real" about using it. Sorta the good, the bad, and the ugly of the whole thing. Okay, so we're gonna ask you to answer us what you honestly think so that they can take this information from a lot of families, a lot of users, and a lot of people who've worked with it. To provide it for folks who are trying to make a decision as to whether or not they want to get involved with it. I really appreciate your doing this today and let's just start in. There's no wrong answers maybe NO is a wrong answer but there really isn't any. Do you remember back before she got these kinds of voice output devices, what sorts of things did you hope that they would make available to her?

MM: Well, we before I knew anything before the Liberators that she got at school - that she was talking. Her goal was to talk. She went to the old school they gave her similar to the Liberators that she is using. So that's when I first found out about communications.

SS: Did you think that when she started using these things that talk like this? What areas did you think it would make things better for her? In her school work, in play, in your family life?
MM: There's a lot of things that it helps with her like communicating with her, understanding if she if she needs something.

SS: So that's really true at home right now. It makes life easier.

MM: Yeah

SS: What parts of it are difficult? Are there any parts that are difficult?

MM: Uhm there is due to we have other kids and they want learn how to use it and she wouldn't allow the other kids to use it. I really don't know all the import/???outport??stuff. She knows more.

SS: So what happens when the other kids what to use it and she won't let them?

MM: She'll take it away from them. She'll start crying-she'll let somebody know that she does want them to have it.

SS: Then they get made

MM: Yeah, they'll leave her alone eventually because they know their not allowed to play with it.

SS: What kinds of things like training or how to program it and that sort of thing have you gone to any of them.

MM: Not the real training just the meetings with Marcy. Marcy is the one who tells me how to work it.

SS: What would you say how much do you know about how to make it work?

MM: Not really that much

SS: Yeah there's a lot of stuff in it isn't there? Can you store something in it so that it will say something back?

DD: NO

SS: You still haven't mastered that. Do you plan on doing that?

MM: Probably yeah, because she's using it a lot and me the only one with her most of the time now.

SS: So your planning on learning more. Okay, how does it feel when your learning about it? Is it interesting and exciting? Or is it kinda scary?
MM: Well both

SS: Yeah
MM: Interesting but I know don't want to mess it up cause it seems like if you push the wrong button you will clear it and have to re-program it.

SS: Desire can she program some of it herself too? Does she know how to do some of the programming?

MM: I'm not sure.

SS: Do you?

MM: Do you know how to put words in there yourself? Have you tried it

DM: NO

SS: Would you like to?

DM: YES

SS: You would, so as time goes on probably you'll be learning how to do that then. So you can write in things that you want to say. How much do you use it at home percentage wise and for what particular activities?

MM: Well, we really haven't used to the house over the summer last year and then only on weekends but we had trouble having it there with other kids the so I told Desiree's teacher that we would go ahead and leave it at school.

SS: But when it is home what kinds of things- does she talk on the phone with it? Do you use it to have like a discussion or there particular activities like when she's playing a game anything like that?

MM: Mostly she uses it to talk to her grandma and grandpa when we travel she takes it with her. Tries to use it with other people. It's kinda hard for them to understand her and stuff.

SS: Do you have -- how much does Navaho play into this. I mean like your family are bilingual they speak both English and Navaho.

MM: Her grandparents they're bilingual and my side of the family there're all Navaho and don't understand English and find it hard.

SS: Yeah, and you haven't put any Navaho in it? Would you like to do that if you could figure out how to do it?

MM: Yeah.

SS: Yeah?

MM: It would be interesting for my family to communicate with her one on one.

SS: yeah, that would be good. How about charging it, and keeping it clean, making up pictures for it and all those kinds of things?

MM: Yeah, we plug it in and charge it and keep it clean.

SS: Is that like a real pain or did you

MM: No, that's just something that has to be done.

SS: You just learned to put on a schedule and just do it. What about the pictures? Do you use mostly use the pictures that come with it in the package or do you make up your own pictures? How do you feel about the symbols and that sort of thing?

MM: Well, we use the package that come with it because it's more easier for her to remember which one means something.

SS: What kinds of things does she mostly talk to you about with it? Does she talk about how she feels or does she tell you what she or is it just like information- like what outfit she wants to wear or is it all these things?

MM: She talks about mostly things about how she feels. What happen at school. Where she wants to go and whatever she can remember she'll say.

SS: Does it help any if things happen and she's mad or she's sad and you really aren't sure what's gone on. Is it useful then or?

MM: She has a hard time talking about her feelings at times. You gotta ask her how she feels and if she gets hurt. When she's hurt she'll tell you.

SS: And she uses the Liberator, that's good. That's one of the positive things then isn't it yeah. So all your training and all your information about it is done through the school here. When you make decisions about how it's going to be used you work as a team?

MM: uh huh, yeah.

SS: And that works pretty good? Who purchased the device?

MM: Yeah, I believe it's the schools.

SS: You didn't have to change the way your house was arranged or anything thing like that to accommodate it?

MM: No, No

SS: Where do you put it when you charge it?

MM: In -on the counter in the kitchen. It's high enough the other kids can't get it.

SS: Um, this kind of information will go out to people all over the country so if you could just visit with another mom and say to her. These are the things that I think you should think about what would you say?

MM: Tell them it's fun for the kid to have so they can communicate with parents. They could use it. They can learn lot of things and express their feelings and stuff.

SS: So you think it's worth it?

MM: Yeah, I do.

SS: Good and how do you feel about this device verses the Wolf?

MM: The Wolf it can only say so many things but the Liberator can count numbers, sing all kinds of thing and stuff like that.

SS: So overall you think life has improved because

MM: yeah

SS: Good, is there anything else that I haven't asked you that you want to tell about it? Do you worry about it ever being stolen? It's safety as far as falling on the floor or anything like that?

MM: Traveling

SS: yeah

MM: It's hard to take the Liberator when we're traveling and stuff because we have all the kids. I have a hard time taking it because of the size of it and it's heavy but that's probably the only thing the problem having the Liberator.

SS: Okay, where do you travel to and how often do you travel?

MM: Well, depending on her doctors appointment going shopping, to the malls and stuff. Going to other states to visit families and stuff.

SS: Does she really seem to like to use it?

MM: Yeah, she enjoys it when she does have that home she asks for it. Weekdays it stays at school.

SS: Then does she use some sort of low tech or something when she doesn't have it? Some booklets and pictures and stuff?

MM: Yeah, she has some pictures and stuff that she has at the house. She uses them cards
SS: But she must prefer to have her own Liberator. So if you were when she grows up you want her to have her own thing?

MM: yeah

SS: This is fun to see since just a little while ago we talked about the possibility of her getting one and it's really nice to she her have it now. How much she's growing.

MM: Yeah, she learned a lot from the Liberator. She knew how to put in all the words. She reads books with the Liberator. Does words her math.

SS: Does she sing?

MM: uh huh

SS: What does she sing? What kinds of things does she sing?

MM: Do you want to sing? Remember how to make it sing?

Desiree pushes buttons and then there is voice output from the Liberator

Group laughs

SS: Not too bad. Well, we gave it a shot. Is it supposed to sing happy birthday or something like that? yeah?

MM: She's sings Christmas songs during the Christmas season.

SS: Good, so overall I get the feeling that your saying that you would encourage another family.

MM: Yeah, yeah I did that with the wheelchair. Go take it to the clinic because these other people with their kids aren't the same. She'll be the only one with a power chair and the others all have manuals. It's about the same things as having a wheelchair.

SS: Good I really appreciate your doing this. I think that pretty well sums up. So she plays with it. She does school work with it. She controls her environment with it. Is there anything that you wish it would do that is doesn't?

MM: Speak Navaho(Laughs)

SS: Yeah, exactly wonderful that's right and I think it can I think it's just a matter of putting in the time to get the Navaho translated into phonemes so that we can get it in there. So

MM: I think they tried it before. I think it's able.

SS: Well I did a little bit that time I was up here. I was awfully proud I got tow phrases or whatever we got in so. What in Navaho of all the things that she might be able to say what kinds of things would be most important?

MM: Like to say hi hello and name her clan.

SS: Her clan yeah, and to say hi to her grandma and grandpa and before she goes to sleep.

SS: Do her social kinds of grandchild role with your family? Well that's good because I think that's terribly important and the more that you get this sort of real data telling people that that is it.

Okay I think we're done

Structured Interview With Navaho Family

February 16, 1996

Sheila Stuart, Ph.D., C.C.C.
New Mexico State University

Summary Background Information

Type of Group: Structured Interview with Navaho family members who use AAC; conducted by Dr. Sheela Stuart, New Mexico State University

Date Conducted: 2/16/96

Where Conducted: Shiprock High School, Shiprock, New Mexico

Number of Persons Present and Roles: Michael Yazzi, Nathaniel's 14-year-old brother; **Rosie Emabanalli**, sister to Emma Curley (Nate's mother) and Interpreter; **Emma Curley**, Mother; **Nate Yazzi**, AAC user

Logistical Issues: Translator present; the primary concern was establishing rapport (trust) in light of the abstract, highly educational tone of the process impacted by language differences. Therefore, the facilitator tried to demonstrate credibility by presenting the family with their check prior to beginning the interview. Also, the facilitator asked careful and thoughtfully-constructed questions coupled with effective listening as the family talked. The facilitator was respectful of the slow reaction time of family members to questions posed to allow for maximum personal response.

Modifications Required in Protocol: Just as the interview began, the older brother came and requested to be included. The facilitator modified the original set-up to accommodate this needed change. Translator/Focus Group standard operating procedure is difficult (e.g., the mother seemed to expound at times when the translation seemed very short). At times, the facilitator needed to include the brother and aunt by directing questions at them. The mother always answered *first*.

Synthesis Statements

1. Balancing Child/Family Needs (not just communication)
   - Family amazed and joyous to get device
   - The communication device viewed as important , lets child communicate needs, wants and feelings with family, but also very important ("makes a big difference") how to go the bathroom by himself

*All three important to family
  1. Communication
  2. Self Help (toileting)
  3. Mobility

2. Family Knows Child Better with Device
   - Communication device helps family to know him as a person
   - It is worth it-they can communicate
   - Lets family know needs and feelings

3. Family Needs/Goals
   - More Navaho words on device
   - Wants computer so he can write letters to others

Transcript

SS: Would you tell us who you are?

M: Hello, my name is Michael and I'm Nathaniel's brother

SS: How old are you?

14

SS: And you go to what school?

Shiprock High

SS: Is that where Nate goes too?

Yes

EC: My name is Rosie Emabanalli and I'm a sister to Emma Curley and I'm the Interpreter

SS: Okay, so your really playing two roles here. Your going to translate for us and your also Nathaniel's aunt.

EC: Yes

SS: Okay, the question that people want answered in this discussion is the good parts of using augmentative and the parts that are hard or that you wish were different, so that when other people make up their minds as whether or not they are going to buy one of these pieces of equipment. They know really what it's been like for you as a family. So, do you remember what year was it when you got this device?

EC: 89 or 90

SS: Okay, how did he communicate before he got it? Did he have a different kind of way out output or did he have a different kind of voice output or did he just sort of talk and she figure things out?

EC: Well, um he went to school there to huwatchy and during that time he didn't have any device. So he had to communicate with either a yes or no answer with a nod of the head.

SS: So, when she first heard about these things and Michael you too, when you first heard that maybe you'd be able to get one of these things for Nathaniel. What kinds of things- how did you think it would make life better? What were you expecting?

When he was at tohatchy he didn't have these kinds of things, so there was no communication with him, but later they had sent him to North Dakota and all these things he had learned and he had the computer and it make a big different. Its more like your communicating with him and where he understands you. She went there and she saw all these things and how kids over there. They were learning how, they were teaching them how to you know when they put you know working on computers and all these things and then even teach him how to use potty chairs and going to the bathroom by himself, and so she said it makes a lot of difference.

SS: It makes it better?

EC: It makes it better for him to communicate and everything.

SS: Good. What do you think Michael? Does it make it better?

M: A lot better to communicate with him.

SS: So you feel like maybe you know him better as a person?

M: Yeah.

SS: What do you think Nathaniel?

NC: Easy.

SS: Easy? Your pretty good. I've met some people who aren't quite as good as you are at it. So over all, it's worth all the time, but tell us about maybe some of the things that are hard about it. Can you tell us things that you wish were different or better?

He went to Boarding school for two years at the Society and they had a computer there called Macintosh and with that computer he can even write a letter or whatever he wants to say. He can communicate in that way, like he can write a letter to somebody on that computer and she would like to have some like that where he wouldn't forget what he has learned. That the only needs that she has for him.

SS: Michael is there something that you wish he could do? Did he talk to you about girls?

M: Well, like she said he wants his own computer that he can have at home and I mean not just the one that he borrows, but of his own so that he can write to his friends. Like in Jamestown stuff like that.

Okay, now if there's a family in Oklahoma that has somebody who might want to think about buying one of these things or working with this kind of stuff. What sort of advise would you give them. What would you tell them? Would you say it's a good idea would you say

EC: You mean if somebody had a child like that and if that child didn't have something like that and okay.

SS: What kind of stuff would she say to them?

EC: Well she said that there was a lady with handicapped child that um what was his name well he's the one that was working with Nathan and sent him to North Dakota and he knows about all these things. He wanted her to meet with this lady, the one with the handicapped child, to talk to her to encourage her that to help that child were he can, where she can improve more. So she said she wanted to meet this lady over there at the hospital somewhere, she talked to her about a boy that was handicapped and he=s been to North Dakota and how much he improved and they could they communicate with him and everything. Well she said she talked to this lady. The lady didn't want to give up her child but she did encourage somebody to do it.

SS: So she'd say just put up with the learning and put up with all the stuff because it's worth it.

EC: Yes

SS: Well, how about you. How do you feel about it?

EC: I think it's great. We can well, I was kinda shocked when he came home and well I heard that he could speak in a computer and I though how can he speak in a computer and I heard about it when she got over there and how they could communicate with Nathan and she said that he can write a letter and I thought wow. So, I think it's great.

SS: Then you got to see him do it.

EC: Umm. The first time I went to his house I said, 'hello' and he said, 'hello' and I said, 'what my name' and he used to say my name but I guess he didn't know how to spell it so he couldn't of spelled my name but I though it was great because you can communicate with him very easy he can talk to you if he's really low or if he's in the need of something he'll tell you.

SS: Good, Michael do you got anything that you want to add? Don't have anything that you want to say?

M: Well, like she said I was a little surprised too. When, well I went to North Dakota with my mom and when we saw him he said hi, how are you? I was amazed.

SS: Yeah, I remember one time somebody that I had worked with a long time, got a voice output device and they called me on the phone and I just cried because it was like something that I'd always wanted. You know to be able to talk to them just like you talk to anybody else. Now that was in Lincoln Nebraska. You've been working over there. Do you want to say something? Okay.

N: This computer has failed to operate.

SS: That's the final word what more could we ask for we really appreciate your coming this afternoon. Oh, I do want to ask, I understand that you do do some talking in Navaho although the computer don't talk very good in Navaho, right.

EC: No, the computer don't understand Navaho but Nathan does.

SS: So if you could everything that you ever wanted in your life that might be something you would like for it to be able to speak Navaho and sing in Navaho and something like that? Would that be fun? Yeah. Well, we like to tell people that because they are always designing bigger and better things. So maybe they have one or maybe we can do a research project to get it to be able to get it to say some things.

EC: Well, I think if you know Navaho. How do they put down the language? How do they do that?

SS: They do phonemes. Little tiny sounds and then they put them together and do what they call text to speech. In other words they type in the letter and then the phoneme .

N: Excuse me may I say something?

SS: Of course.

(Over a minute pause)

Don't think it's a toy.

SS: Right that's something else that you'd like changed. You would like people not to think that it's a toy. I see sure, that's good information to have.

EC: She wants more improvement on the wheelchair, one that he can control himself and he probably has one at school, but she wants one that he can use at home because of his feet tied down because his legs and their grown so he can't be always bending, so she wants if their could be any kind of improvement on his wheelchair where they can help him in this way.

SS: Okay, it never hurts to ask. Okay, I think we're done unless somebody else has something else to say.

EC: Well he's going to school here. He could learn a lot. He's learning but the aids that are working with him, well I just heard that today they're not working with him in the right way so to me that's not good. I think they need to do somethin about these kinds of things for the handicaps because I have heard other people complaining that just because the child is a handicap doesn't mean that they have to put them aside or treat them differently because I know Nathan has a feeling and he needs to be with the kids and treat him just like everybody else and help him to learn the way he should learn. And when he learns he learns a lot. He know a lot. Like one time he even wrote that down. I'm not a dummy, I have a feeling and I can do so I wish at the school.

SS: I appreciate you saying it. Okay thank you very much.

Structured Interview with Family Member of Child without AAC Device

April 19, 1996

Nancy Dunn, M.S., C.C.C., Moderator
Arkansas Easter Seal Society

Summary Background Information

Type of Group: Structured Interview with family member of child without device.

Number of Persons Present and Roles: **Anna Johnson**, mother of 7 year-old child with Wolff-Parkinson-White Syndrome with Chromosomal Anomaly who is currently enrolled in a self-contained CBI classroom at North Little Rock Schools. A Delta Talker has been recommended for the child.

Date Conducted: 4/19/96

Where Conducted: Augmentative Communication Lab at the Arkansas Technology Resource Center at Arkansas Easter Seal Society.

Logistical Issues: Five other parents were scheduled to attend the focus group and Ms. Johnson was the only one who attended. We scheduled approximately 2 weeks before the groups and called to remind a week prior. One parent did call to say she was not going to be able to make it. The others just did not show.

Modifications Required in Protocol: Only modifications because only one parent was present.

Synthesis Statements

1. Family Expectations
   - African American mom wants child to communicate better with others
   - Mom is anxious to receive device

2. Impact of Devices on Mother
   - Mother must learn to use device
   - Mother must teach child how to use device
   - Mother fears having to take sign language classes

3. AAC and Changes in Home
   - Being able to communicate with other children in home setting may affect home organization
   - Learning to use AAC device is not seen as a demand on African American mom's time
   - African American mom feels AAC device will eliminate stresses associated with trying to understand child's needs
   - AAC device will allow child to interact with mom's boyfriend

4. AAC and the Community
   - African American mom does not anticipate changes with others in community after provision of AAC device
   - African American mom does not anticipate child's ability to go out into community being affected

5. AAC and Working with Professionals
   - Mom wants professionals to explain everything regarding AAC: need for information
   - Professionals should not use jargon
   - Professionals should consider compact and easily transportable devices for smaller children
   - Professionals should examine the child's home environment before prescribing devices
   - Mom wants device that is:
     -safety proof
     -has larger keys
     -has larger words
   - Mom is unfamiliar with funding process
   - Mom is offended by use of term mental retardation by professionals

Transcript

My name is Anna Johnson, I am Latoya's mother

ND She's just been evaluated, right?

Yes she's just been evaluated. Phil cam out the other day and he was telling me that I had to write out a CMS Medicaid for her to get a device and telling them why I do feel she needs one, which I feel that she needs one so because she can communicate but with her not having, not being able to talk it makes it very hard because then like onetime she fell the stair outside and I believe had the device she could have told me she didn't feel good and that she was dizzy, but with her not having a device and no way to let me know how she felt. Then once we got back into the house, the only way I knew was because she almost fell out and hit the table and once I got her to the hospital she had a concussion.

ND: What a kid

She was running around the next day like nothing happened. She just something else, she is.

ND: What are your goals or expectations for the device she going to receive?

To be able to communicate with her better. To be able to, you know like I was telling you that there was two other kids, well three in the house and sometimes they all still get into it. They get along good now, but they still get into it. If one of them hit her or something. Like she could come and tell me, she'd be like uhuh, like that but she'd then she'd point to them and they'd be like I didn't do it. You know and she can't tell me which one of them did. So you know I expect that it will be for her to communicate with me.

ND: Do you see when you get the device do you think it will affect the roles that you must assume? Like now your the parent, your mom, do you think you'll have to take on different jobs when you get the device?

Yeah, because number one I'm going to have to learn how to use it, to help her use it. Philip told me I could take some classes which I know I will need. I was kinda scared cause I thought I was gonna have to learn sign language. I was going like that's a lot, so yeah I think a few things will change.

ND: Do you think it will affect the organization of your home environment?

Yes definitely, yes with her being able to talk and communicate with the other kids. Yes it will change tremendously.

ND: You just answered that, but do you think that will affect the relationship with family members?

um huh, yes

ND: Do you think it will affect the demands that are placed on your time??

No, no, except you know me learning how to use it, I don't think that's a demand on my time. Learning how to use a computer and everything, but other than that no.

ND Do you think it would affect the levels of stress that you currently experience?

Yes. Yes, yes, because I get frustrated like if she's trying to tell me something and I don't understand what she's saying I you know I have got her to where now if she's trying to tell me something, then she's say come here. She's do like that. You know, then she'll point. It's frustrating at times and like if she wants something she'll you know. Well, now she goes and gets glass and come to me and go mmmm.

ND: Do you this it will affect your relationship with others especially out in the community?

No, No

Do you think it will affect your ability to take her out in the community like to restaurants or other social or recreational activities?

No

ND: What has been your greatest concern in working with professionals in getting you child's device?

I really don't have one cause everybody has been so cooperative. They made sure that they explained everything. Philip, you know everything get across too me really good.

ND: What should the roles of the professionals be when trying to work with when trying to get your child a device?

What should they do? I don't know, well you know, just like I said everybody said pretty you know as far as I just want to be able to understand everything . I don't want have to go and do something wrong or something . Oh yeah, all those big words they be using, if they could find a way to break those down, than would be wonderful.

ND: What things about the device that are important to you that were not considered by professionals?

If they could get a smaller carrying case like that little mini one I've seen. Like, cause she's not that big, you know, and I can see her trying, might be having a little bit of trouble trying to run around outside and play with that thing. She needs something compact, that she can run around with.

ND: If you could you tell professionals how to better work with families when trying to identify devices what would you say?

Um, to come out to their houses, to see the atmosphere of the house. I believe that sometimes you know I believe that would better be able to suit them for what kind of computer. Which one they should be able to get for them because I might have a little bit of trouble trying to keep the other three away from hers or it will always be in the shop.

ND You prepared for that

Yes I'm prepared for that one.

ND: How if at all are the values or beliefs of professionals are different from yours?

No

ND Is there anything else that you want to add?

No

ND Is that anything you want us to know? How it affects your family?

I think it's going to be a good effect because she likes to mess with my boyfriend a lot. When he gets in from work she's the first one there. She just. He'll be like girl get away from me and she just laughs, I just don't know.

ND Well you already said if they should come to your home. That's an important thing to know.

Yeah, yeah I that will be good and if they could compact the computer.

ND More portability.

Put some kind of safety case over it you know so the other kids could be able to get to it. Well I don't know cause she hasn't go her eyes checked yet, but if they could make those slots and those words a little bit bigger so they could see them better

ND Did you want to say something Ginny?

No, I was just wondering in general anything as a parent?

I can't think of anything cause when we came up here and was evaluated it was just perfect for her.

ND So you haven't had any problems really.

She's gonna love it. I know she it. She has one at school. They started her working with one already.

ND Have you thought about the concerns at school, when she's at school?

No, no. she does, she does pretty good. She really does I mean, I don't have any concerns I just want her to hurry up and get it. So I can start talking. You know I was talking to my boyfriend.

I was like do you know that when she gets that computer, boy we're gonna have to make her go to bed. I can tell, I can see her just she got she much to say and she just can't say it and she tries, she tries so hard know it would be good for me for her to have it. I can have tell her to go tell somebody else something. Like I sent her outside to get her little brother the other day and she stood on the porch and she aaaaa, like that. I got all her little vowels. I can get them all. I know them all and he just stood out there. I knew he knew what he was saying, but he was like, just out there and then she came back in and uuuuu, kind like you know he wouldn't come. Then she went out there and get him. So she went out there and she got him by his shirt and she was pulling him in the house. She understands good, but I believe that will be real good. She can just communicate more. I can tell, she just always u u u and she sings her little songs.

ND What do you think about the whole funding process?

The what

ND The funding, you said that Phil said was having you write a letter. Has that been kinds difficult?

Yeah, I haven't started on it yet, because I know when I do it's gonna be something.

ND Did you have to take her to the doctor and get the prescription and all that stuff?

Yeah, he said that we was gonna, but I think that he was supposed to be doing that, but he helps me out a lot.

ND He's your case manager, right?

Yeah, he helps me out a lot. I mean he's a really good case manage because if I can't get to meetings or evaluations at school or something he always makes sure. He always calls me. Well can you come, because if you can't get there then I'll go or of if he can't make it, he'll call and we'll work out something so that one of us is always there.

ND Good. so that's something that you really like.

Yeah, that's what I'm saying, everybody that I've had to work with her and about her, they've been wonderful.

ND That's good.

I'm lucky, I haven't ran into not one with an attitude. Like one time we went to evaluation at her school and the lady was telling me that we're going to have to labeled her as partially retard. I was like my baby ain't retarded and she was like no, no, no, don't get offended, but you know we have to put this on the paper s in order for her to get the things that she needs. I was like okay, but all in all I was glad that ya'll came up with this cause I was like I didn't know anything else to do, but the fact that she was going to have to learn sign language and I knew that if she did than I did too and her brothers was gonna have to go and learn. She had a 13 year old brother too where he's not living in the home with us, but he's there when school's out like in the summer time. He'll be there all summer and I know that he'll love to help her with it. He'll just have her running around saying something to everybody.

ND So you thing the brothers and the kids in the house

Yeah, they're gonna definitely try to help her because they don't want to play with her and that's their excuse to play with her. They know the only way they will be able to touch it is they're gonna have to be trying to teach her something. Yeah, let me do it, I'll show her.

Structured Interview with Dutch Family

August 14, 1996

Mary Blake Huer, Ph.D., C.C.C., Moderator
California State University-Fullerton

Summary Background Information

Type of Group: Structured interview with Dutch foster family members, **Gaya Williamson** and **Am Va de Heide**, who have a child, **Robert**, who has been placed in their home for five years. Robert has a neurological problem and speech disability. He is currently learning sign and knows approximately 36 signs.

Date Conducted: 8/14/96

Where Conducted: Family home in Monrovia, CA (outside Los Angeles)

Logistical: Was unable to have family meet with information-gathering team outside the home. Considerable travel and prior preparations were required for team to go to home (e.g., use of cell phones to communicate with one another, conversations with persons in community regarding colors worn by local gangs to ensure that a 17-year-old team member serving as camera man would be dressed inconspicuously and not become a target for aggressive behavior).

Modifications: Deviated from protocol by allowing family to discuss tangential issues of concern to them. Was able to touch on issues related to AAC, though family's primary concerns focused on their expectations of the service system.

Synthesis Statements

1. Family Concerns Regarding Child
    - Would not make eye contact initially
    - 3 years required to establish bond with child

2. Family Preferences of Communication/Concerns
    - Child has neurological problem and is learning sign
    - Oral speech is sometimes distinguishable
    - Family prefers oral speech to use of sign
    - Family expresses interest in speech device with large amount of available memory

3. Family Concerns Regarding Professionals
    - Want professionals to be consistent in use of appropriate interaction styles with child

- Want professionals to use/language that is not dehumanizing (e.g., referring to child as a "puppet")

4. Family Concerns Regarding Service System
    - Child is moved frequently among school due to poor toiletry skills
    - Family wants acknowledgment and support from natural parents
    - Family wants to feel that the service system values the child
    - Support services for family and child should be strengthened
    - Family wants to be acknowledged that they are doing a good job with child

Transcript

MH Purpose of us talking tonight is to talk about children like Robert and in particular to talk about your individual experiences with Robert and to tell your story if you will. The interest in this grant project is to focus on children that have communication problems, typically children that have a disability such that it results in the lack of speech. There may be some speech as there is with Robert, but typically where children don't have speech that they use functionally. That what we're really focusing on is families experiences. What happens when you have a child who doesn't use speech for communication. What your aspirations are for their communication. What your experiences have been. We just kinda start to talk and there are a few questions that I will try to ask if we haven't talked on that. It's just really a dialogue where we're collecting information. There is no wrong or right
answers, just to get your story.

W Resource of information

MH This will be shared with other families Pieces of it will be compiled so that if other families have children similar to Robert or others they can have a resource to go to and get information from families instead of just the professional perspective. We're also talking to manufacture's who sell assistive technology where there are these devices that actually speak. We're talking to professionals. We're talking to teachers, speech language pathologists, and occupational therapists. There's just a large array of individuals that

W When you all put your head together that must work

MH Well, we would hope so. We would hope that certainly after this we would have more information than we have currently. I will let either of you start to tell me a little bit about Robert. His history, some of his diagnoses.

W I think I will start off. I didn't expect him at all. We had a call at 7:00 o'clock at night from the area airport social worker that first the where he should go to. So we said, well yes bring him until you find him a home. I guess he didn't find a home. It's five years later.

MH Wow

W But when we came and got him. He was all taken all over. The whole day in a plane, Pennsylvania-New York, New York-Los Angeles.

MH So he was born in Pennsylvania?

W No he was born here, but social service talked to the mother and grandmother that he was so neglected that after Christmas he would go into a foster home. His brother was already in a foster home. He is a year younger. They took off with him and when they came to Pennsylvania they asked money for him and they sent him back to California because the state didn't know what to do. So when he came here on the airplane with them we didn't know what we had. We didn't know if he had seizures or not. He was taken all over, dirty and hungry from the whole day traveling and so we put in playpen and there was plastic end. He crawled on the plastic end like a little doggy and he wants to lay there. Now afterwards I hear he never had a bed before okay so that figured out what he did. We had Kisha and another girl move the two beds and let him sleep in the middle and in the middle of the night he crawled into Kisha's bed. That was the first contact that we had with Robert.

MH How old was he at that time?

W Two years old

MH Two years, so before that he had just been in homes?

W No, mother

MH His mother?

W So then he could go to fifth avenue school and they know him. He has gone there when the mother had him and he could go five days a week instead of three days because then got a meal. He never had milk either, always cola. So he was completely his body his stomach was all water milk was not in the picture at all. After he has gone back to the school he was before and get to know us better we never have really called the service to come pick him up. Because that is what you know. You fall in love with a kid, see so they left him. We battle them a little because they classify him as a regular boy.

MH Oh, really

W Yes we still don't have what somebody else get. We don't want to make to much trouble because he needs a lot of love and care, but they have handled us very, very badly.

MH The social services agency? Have you had other foster children?

W Yeah, for a while between her, we both are foster mothers. Between both of us we had ten for a long time. Two homes next to each other, yeah, for years but he beats them all. He's 24 hours care.

MH Were they special needs children?

W Yes, we had Ausman- brain tumors for cancer. We have two little ones McChance, who had broken ribs from the hospital, severely beaten and the hospital called me often to pick one up and

MH So there's not a lot of notice it seems?

W They know where they can call. You know? Yeah, but Robert is so far the first from the other half. It is 24 hours and you be glad to get a couple of hours sleep with him.

MH You two just take turns, the two of you kinda shift him?

W No she works full time. She sleeps in her house and she take one or two with her up to ages of that boy because with all of the girls that boys sometimes likes to go out of the house. I have asked for a new bed for Robert. He was in the hospital and he had a beautiful bed but he couldn't get out. That was oh far before April and the judge said yes you can have a bed to the lawyer for him and we haven't got anywhere. No where. I called the social worker and she said, well in paper it easy enough to get one and I said oh do your best. When he has a bed he can not get out. He can not get himself in trouble because he eat lint. He eat little toys. He bite wood splinters and everything, but we watch him all the time. We've had him know for five years and we've not had one accident so let me knock on wood. We do very, very well, but care for him, a lot of care for him because not only is he from the state, but he is a lovable child. You don't want him to get hurt. He is worth fighting for, but what the future will be with Robert is you know it has to be seen what's going to happen to him and then we could get help when we need help we will take it with both hands, yes.

W2 When we got him (some input) When we got him it took us 6 months before we ever realized he had brown eyes. He would not look at us. He would not communicate with us. He would not be affectionate. It took us 6 months before he would even ever look at us. Now he is hugging and kissing, but it took a process of at least 3 years to get him to be that affectionate.

MH And his ethnicity is?

W2 A mixture of

W The grandfather was black and the grandmother was white and they had one daughter. He's a product of the daughter, but 3 more. Two more girls and they all are handicapped and the second one is worse than Robert and have different father. His brother is black as coal. He visits here.

W2 half brother

W Robert they say has the Mexican father, but the doctor he says he could have an oriental father on the ways the eyes are standing. So I don't think they really know who is the father. There is a Mexican man on the paper, but that don't mean that much. She was only 15 when she got the boy.

MH Then she just stayed with him for a couple of years and then he went on into the system it sounds like.

W2 yeah he went on into

MH Now tell me then after you were able to work with him a little bit you started to seek out professionals to find out his diagnosis and his capabilities?

W2 No we didn't.

MH You put him in schools or how did that

W The system had put him in special education immediately.

MH In the preschool program immediately.

W2 In the preschool program immediately with children like this they put them in preschool programs immediately and he goes to school 5 days a week. The bus picks him up and he is in special classes and so they inform us very little really what background or history on what medical conditions are. You usually have to find out my hit and miss with the child.

MH So has anyone diagnosed him with Autism officially or just?

W2 Borderline, they've not done that. He has a neurological problem and then also he has a speech problem and so he's learning sign language. The communication gets both sides very frustrated because he can't communicate what he wants and he can't answer what he wants. It's a hit and miss on communication.

AJ He knows 36 signs.

W2 We pretty well know Robert.

W He go to the kitchen and ask for milk. Words sometime are very clear and some words. Like banana he has a certain way of doing that. We have a paper and we shake the paper in certain movements with his fingers.

MH How's his hearing? Has his hearing been checked?

W Oh excellent. Too much

W2 We have a discussion. We can't say the word, but it's in the backyard where there's water.

W We cannot say where we go and I say

W2 If we say that word, he's in the drawer getting the diaper off putting on the trunks to go or if I well have to go and get some food at the stores.

W Watch your language

W2 Shoes come out of the closet and he's ready to go.

W Even when he plays. He hears us talk out here. We're out he and he hears the keys he runs. He's very alert.

MH So he's been with a speech therapist for the last 3 or 4 years?

W2 Yes, they're teaching him sign language and the speech therapist in the school he's at through regular education.

MH Do those therapist speak with you frequently? Communicate with you?

W No, the teacher has been here twice.

MH I see

W She came to visit here and she was surprised at what he did at home and not in school.

MH So he does more at home?

W And I was surprised at what he did in school and not here.

MH Really

W For instance, she said he can write his name and I said oh no he can't. We gave him a pencil and we said write your name, no way, but the school he does it. He is always here dancing and jumping and doing what he not does at school. There is two kinds of boy.

MH That's interesting

W But yes, she was surprised when she was here. How lively he is. How active.

MH He's more calm when he's at school.

W Well, yes so now we've figured out that there is a lot of pressure at school. you sit down and write. We don't have that pressure, you know what I mean. We are too

MH Very permissive and lack structure in terms of it's a different philosophy.

W I can not grab him when he do something special I will put him here and I will say this is your penalty to sit here- time out. And he will sit here in my protest. what can you do to a child that is so delayed to punish him? you cannot you don't need punishment. He needs love. He needs understanding, but he needs love. What can you do?

MH So a part of the collection of this is to seek out a description of the relationships between school professionals and family. It sounds like maybe there's some frustration with school professionals with the styles of interaction.

W yes, yes

MH I don't want to put any words in you mouth, but can you expand on your perception?

W The school is not a favorite of kids or Robert. We put him in. He got from one school to another and when he was there a short time. Good teacher. Loved the school. They say well he is getting to big. He has to be moved to another school. Okay so we moved him to that school. That teacher called me one or two days after he was there. He is in diapers and he is the only one in the class. I said well I cannot help that. But he's into papers. Okay, well she did not like that. He is there about 4 weeks. They called he's going to be moved again because that isn't a class where he fits better in. What are they doing with the boy? That's not in his interest. I said to the principal why did you move him from that good school where he really gained to that school where he is now. He said, well that class was too big and now Robert has to go. I say wait a minute, when you pick on foster kids you get me at your neck because Robert has the same rights, but now
in September he has to go again into another school.

MH When they move and make these decisions do you have meetings? Do you discuss it?

W They a lots of time call and say we're moving him. That's it and I say

MH Aren't there IEP meetings?

W2 There are some meetings but

W Yes, there are some meetings but they are nothing to do with moving him. We come to a meeting and the teacher come to you and say we can keep him for a while because he is doing so good and that was his birthday week. I said we will send cupcakes to school. The day from the school from his birthday there came a strange bus and moved him to another school without questions asked. Now for a whole week he has to be bused, refused and it was all wrong. So I called the principal and I said now are you going to move him again? Where are you going with the boy and when are you going to stop? But no there is something drastically wrong. They pick him up like he is a puppet and that's not the way we want it. The last year has been for Robert, but he's a boy. He's everybody's friend. He don't mind being moved from school to school, but when I have a good school with a darn good teacher that came here twice and explained and loved him. I saw that then you should leave him. When there are reasons to be moved don't do it
after 9 or 10 weeks. That is dumb, don't take him. So

MH Is it his age? Is it his height? Is it his size?

W The diapers.

MH The diapers?

W yeah, the diapers, we have now 5 years and we catched it three times and he was on the potty this week.

MH IS that do to the neurological involvement do you think?

W2 or being lazy

W and he's also not aware of it because this week he sat on the pot and I go and get a chair and I sit in the same bathroom. I say now you are going to do. He was dry. He was sitting there at the time. A couple of drips and he looked and he stopped and I said go on go on I've got some raisins for you or something and he did it. So that is 3 times in 5 years, that's not much.

MH You try to schedule training in terms of taking him on a certain schedule?

W When he is dry for a certain time we bring him to the bathroom.

W2 We can sit there for 45 minutes and he won't do a thing and we put a diaper on and he's wet.

W He's like a doggy. He smells a diaper and he does it, but I think eventually he will click because I never give up on kids. He will.

W2 Once your hooked your stuck.

MH I want to talk about the speech therapist a little bit more. What kinds of communication goals or activities have they tried or suggested? Does he get direct speech therapy?

W He get speech therapy. I don't know if it's everyday because he's moving so often.

W2 It was 2 times a week.

W That's not too much. That's definitely not enough for Robert.

W2 In the meantime with the speech therapist he is also being taught sign language. So I think they were off setting the two.

W Yeah he can talk. Don't tell me he cannot talk. I listen to him on the monitor at night.

W2 He can sing

W He can sing and the words are not very clear some of them he will learn. He will.

MH What are the obligations of the school to provide services for a child who needs services for a foster child? I haven't had a lot of experience with children that are foster children.

W2 They should be equal to a regular child.

MH If a speech therapist made a recommendation that he needed certain services then just like any other child on his or her caseload that should be provided by the district?

W2 Yes, this child should not be treated any different then if he was born from me.

MH Do you sense that he is treated differently? Do you know the other parents?

W No, but I have experienced with our girls. They treat foster kids different none the less. So why wouldn't they

W2 We have found it through regular school systems already.

W Hurting, hurting very much hurting what they do to the kids. When they do it to Robert we don't know because he doesn't talk, but we have a girl and he was very bad in school. We had her for years. She got a teacher in a class and said I love it. I love it. Two days later she said they placed me in another class and I said Why? this class was to full. I broke my neck to get to the school and I said what's going on? She like the teacher and we're having a hard time with her. Why move her? Well most of the time foster mothers don't care when you move them. Now that is no answer.

MH Is that what you were told?

W Yes, now I says wait a minute. You put her back or you get me on your door everyday, but that's what they do. I think that she's right was she told me. I don't think they go and fight. they don't fight for them. She said well most of the time they don't care. I said believe me I do.

MH Was this a principal that said that or

W Yes and I had to dump him a bit more and three months later he was fired. Let it up to me.

W2 We have he board of education across the street.

W She's my neighbor.

W2 She our neighbor

MH That a good position to be in.

W Yes, I said the kids have a right now we tried to break the cycle from welfare and foster care and here we need all the help we can get and we can get pushed out. I said that's not going to happen again. Yes the schools and some social workers they speak up more. They really should speak up speak of things they should not speak. They speak up and get things wrong. But there's a sad story. Now we were 24 hours with the boy why cannot people give us an instruction and tell us when you will do it this way or we're going to do it that way. What do you need? I been since before April asking for a new bed for him and he granted me one because that is one that it protected. You need permission because you cannot tie him up or bend him down. You may do nothing. That is not the boy to be tied down because.

W2 He is like a magician. He'll get out.

W He will get out so now I got better proof and she said well on paper it's easy but to get it is another story. Why don't you call. I didn't get anywhere, but I'm going to call the court back and we want to see that we get a bed for him. They spend so much money on different things. Why don't the kids get more care?

W2 Robert

W It's on the end of the shelf. The noise from throwing the books and then after it is out on the floor he's not looking at it anymore.

MH So he doesn't do the reverse where he puts them back in a stack.

W2 We're training him

W He had the box of toys and he throws it out all over. You can't even get out and then he leaves the room.

W2 If you play a game with him. You want to go swimming you bring me the toys and then one by one he will pick them up.

W You have to tell him there is a red car, there is a yellow car and then he will go for another one. It takes about an hour to pick up all of the toys but he get it done. So we don't punish we make it a game. We absolutely make it a game.

W2 What Robert also does is that when he plays with cars he will line them up to perfection. a straight line or with little blocks they will have to be exactly lined up. He will line them up on the rim of the chest just exactly and then he gives them to me and I have a little table to put them on. Red car, yellow car and then I put one upside down or sideways. He'll come back and scoot it over and look to me like you goofed it. He wants it perfect. Now what is in that mind that want things perfect. That is strange. It sounds strange.

MH It sounds like it is that Autistic like behavior that you see that sometimes people don't understand.

W2 But he is very loving. He's very, very lovable.

MH Another question that we're asked to inquire about and that is socially when the child is away from their family like out in the community. Like if they are out in the park or if they are out at a fast food place if there are any changes or any stressors or any concerns that the families have when in a social situation that you would need.

W2 We have had one time in a restaurant

W Yeah, it was music, it was loud music

W2 Loud music and the decoration was loud and people were loud. They had a party and Robert went into totally screaming. We avoided that one particular restaurant. He will sit on the table in a high chair and eat.

W It's pleasant

W2 It's pleasant. We've taken him to the beach. they've taken him to the movies. He sat though the whole movie.

W They fed him popcorn during the whole movie.

W2 They fed him popcorn and he sat during the whole movie. So we have experienced that.

W We always take him. We don't leave him home.

MH So what you see as far as at home and when he's out in the public is the same with this family.

W Yes, with us it is.

MH Because sometimes there are differences.

W No, no that music in Mexican place and it was a band and was standing right by our table and Robert just freaked. When we will say to one of the kids. That is enough like whatever they do. He goes in the bed and put a blanket on his head. Any loud sound will trigger him off.

W2 He grabs his security blanket and covers his head or his hands or if there is something on TV that he doesn't like. Also there's certain video or on Nickelodeon there's a couple of programs, the beginning he doesn't like and he will put his hands, but still sorted peeks through. That's the only thing that he does that our other kids don't.

W That looks like it could have been a drug baby. You know the way he act and yes.

MH That it could have been a drug baby?

W yes, yes

MH That is could have been a drug baby.

W There was a question mark on the papers. We tried to tell him that it was a good movie and real children's movies cannot do any harm, but raising your voice in the house will trigger him off. It makes him sick. It makes him sick. Not even howling because with 4 teenagers sometimes I have to be as loud as them, but any sound will trigger him off.

W2 When he thinks that there is gonna be trouble he will hide from it.

MH How about back on that communication piece. Do you think that sign language is working for his communication? Are you satisfied with it?

W I basically wouldn't have it.

MH You wish he wouldn't have sign.

W That he would learn to talk.

MH So you prefer the speech over the sign

W Yes, but they say that he may be to stiff and this and that but I think he have two things in that little mind and the sign language come very easy to him and when he could not learn to talk better then he needs it. That's not up to us to decide, but I think that when they really would work hard with him he would talk. He can sign. He will sign for three or four hours. I wish I would have taped it, but who go up at night and tapes singing.

W2 He never cries in the crib.

W He will sit there and talk and sing, but this afternoon he was singing. I didn't know the song to well from Sunday school. It was deep and wide and whatever it was. He was all in it and that American song, America the Beautiful. He sings that now I think that is a very difficult song. Not all the words come out clearly, but I would say 80% that he sings.

W2 He communicates through music a lot more than talking.

W Now see that feet and arms that is in the family. He sings his grandfather has it too.

MH The reason that I'm asking is that there are other forms of communication. There's a few called augmentative communication which is kind what I teach about at Fullerton and what this grant focuses on and augmentative is someday like 25 years from now be it's own special area like speech therapy is. Augmentative communication will offer that. There are a lot of children and adults who don't speech for a lot of reasons. So augmentative communication is evolving in order to offer them a way to augment that's the word whatever speech skills or gestures they have. That's why I'm interested because in addition to sign language there are all kinds of pictures and communication boards people use so a child can point and be specific about what they want. I'm wondering if your attitudes or perceptions toward something like that.

W Now Robert is a ripper of books. We sit there and I say don't rip the books. You see, he will behind my back. What happened to the language situation, we had this discussion with the lady to when you give him a book he maybe tear it up not when I'm here, but your turn your back and it's gone.

MH You can make things more durable with like.

W We have lots of books. He's a destroyer. Maybe it's one of his bad habits. We tell him when he rips a page he has to throw it in the trash and he may not have the book again.

MH There are ways to chart behaviors because sometimes what we think are negative behaviors are really behaviors that serve to meet a language need. It could be that he gets so excited that and then in that excitement he becomes destructive through his excitement. It's like the little kid that slaps the tray when they are excited and the food falls all over the place. They don't mean to do that they're just excited. So things like that could be happening with him too so you kinda have to kinda just watch and see but the purpose of these questions today are just to get people's attitudes toward changes because everybody wants speech. That's the best. Everybody wants it, but not every child has speech.

W You don't know what's in his best interest. You should try everything where they can get their hands on because every child is different.

MH So that would be your approach. You would be willing to do things other than speech but also speech.

W2 Priority would be speech and then the secondaries would be the other ways of communicating.

W Even when there are three ways to communicate that's not right. You know what I mean when it come out. Now with singing he can express himself very well and we push him to sing a lot. I mean we really sing a lot.

MH Sounds like a happy place.

W Not always, but we try. When we sing with him or the girls they have been in singing groups and they have been performers and they sing beautiful so then I say let's sing a little bit with Robert and not a peep, not a word, nothing, not a sound, but when he's in bed at night he. The school said he sit in a circle and you sit there and when it's all over he's just singing or whatever they have done he does it. He's observing it rather than participating in it. It maybe to fast at that moment.

MH Well we know that children learn and then they retrieve. I used to think it was the same thing, but know we know that learning is different then memory and retrieval.

W2 he has a lot of retrieval in there because he has at dinner, his habits at dinner okay we eat dinner and then I come home for dinner and I sit in the chair you sitting in and then dinner table gets cleaned up and he gets wiped clean. The first thing he does is grabs a book hops on a my lap and we go through the book. We look at pictures or letters for about 5 or 7 minutes that's the extent of it and he's off, but it that right after dinner that he wants that lap and a book and it's guaranteed

W He really a lap sitter

W2 Every night.

MH In addition to sign language there are board that have pictures for communication there's actual technology it's um expensive and it's complicated sometimes depending on the technology. It so that when you touch a square it says a word or a sentence. It says whatever it programmed. What would be your attitude toward something like that for communication?

W 100%

MH 100%?

W: 100%, we have some Speak-n-spells but it's been years since it's been operated on. We can't trust baby, but has no memory. Yeah, memory for movies and boys. She's now 15, but for school work and all that she cannot even read. That's the way it is. She is that way, but we have speak-n-spell and all that plenty in the house. he takes it all apart. We have speak-n-spell and we have one that and we have also book that when he push buttons when he push button then songs come out. We buy I would say (Robert playing with a book that makes noise) but now he's completely out. Look his arms and legs and that's so sad. Now you keep your feet still. Robert, keep your feet still. Come baby, keep your feet still. That's a good boy. Yes, good boy. The hospital called him a puppet.

MH A puppet? The hospital?

W The doctor said we called these kids puppets. I said his name is Robert, but see what he does is like he is on a string. His movements. It's so sad. Baby, Baby

MH Another question that we're interesting in capturing your reaction to is values and beliefs that you guys hold verses values and beliefs professionals make contact with. Just from listening to you this evening it sounds like you have different belief systems that are operating and maybe different values that are operating that sometimes clash. Could you kinda of expand or comment on that a little bit. What you do. What you recommend that
parents should do. So we have some conversation about that.

W2 It hard to say what parents should do. We run into the road blocks of people not caring. We give and we care and we get very frustrated with the effect that we get like slapped in the face cause like they don't care. It's just a system. It's just number and that's what is so sad to us because he's not numbers. They're people. They're humans and they have to have the care. So it's very hard to say with parents and children you know their values are very different from ours because we have the road block caring for someone that's not ours and then getting the feedback of well he's just a foster child. That's what our values and anger goes because he is a child.

W I cried one time. I found the grandmother's old telephone number in Philadelphia and got the new one in New York and I know they are poor so I called them and I said Robert is doing so good let me tell you how he gained and tall he is getting. He is doing so good. She said well we're not interested. Why don't you adopt him? Now don't you get a lit on your head when you try. When you try

MH To share his success.

W I never called her again. I'm never calling her again, but that's sad. That's really sad. What attitude is that to a baby. Then I think I spend my money calling New York over three or four operator I got the new number and then why don't you adopt him. We don't want him back. What do they expect? Why don't they say you do a lovely job. Glad he's there and boost me up a little, but I get pushed down and that's not only with the grandmother. I says is his mother there I want to talk to her. Well yes, she sitting here on the sofa. I said well let me talk to her. She came on the phone. Hello, you have my first born because I have three now. I said yes I know you want to be interested. That's sad when we can't even get it from the own family. We need to be boosted up man. We have a hard job. We didn't, we ask for it or we ask to end the situation, but

W2 See when they brought him to us he was a two year old and no information at all. So through the years we find all of these things. The talking difficulty. The muscle movement problem. They don't tell you all of that. We excepted it and we handle it as best as we do.

W We excepted him the way he was. They never came and found another house. We have never asked to find him another house because that's too late. You fell in love with a kid and you don't let it go.

MH The system will just leave him here?

W2 Oh yeah, until we say this is the end. You are going to move him and say you go t 48 hours. Until you push the real panic button

W Why should they

MH Or until they would try to adopt. Would they say you are to close to a child and then move them?

W Oh no they would be glad for adoption of guardianship. They would scoop them off as fast as they could. No questions asked. We been through that before with the other kids and most of the ones that I have are handicaps and need much, much more care than anybody else, but I have the time. I don't work. I'm retired. I'm sitting here and knit. The grandmothers in old story books. The kids sit around me and see the TV or a tape or whatever. They have the warmth that somebody is there all the time. That is very important. The bus driver took them much too far. She passed the street. The new bus driver. He screamed at the top of his lungs. So soon as he passed the street and was lost he screamed. Once he finally found the house here. So he's glad to be home and that's very important. He belongs here.

W2 yeah, but don't take him in the car to the store and you forgot something and you make a U-turn in the street. he screams then too because he didn't get there yet.

MH He's very sequential

W Now we train him potty and it's not success. Now I took him in the pool two years. Yeah, we took him in the tool when he was two and he swim vest and we hold him. On the swim vest you have to have balance and that child had no balance. For two or three years we have him in an original swim vest and we have him on a certain day I said to one of the girls take that swim vest off and give it to me. I'm in the pool. I took him and the swim vest off and I pushed him on his butt through the steps to the water and he swim. Now he swim in the deep water, not official back and forth in the deep. He goes along the side and he swims very well because there is competition. He wants to do the same thing. He went jump roping which was not a success, but he played ball like the big children do. That he is fine in. See there are many kids here. That is why he danced. The teenagers are never sitting still. They are always dancing. He education is teenager education, but four more mothers. They all butter him over. So that boy has a big opportunity here, but when we need help they never send and that's sad. I'm for the play what you said. The
more he can learn, the more he will get the better his life will be. Yes, I'm really for it. Any education that is in favor of the kids we should try and try very hard. It took us three years to get him swimming and it takes me three years to learn him and different things. It works. It works. I tell everybody that he will go into mainstream sometime, They all think that is totally nuts, but no when you don't try you don't get it.

MH That's right there's nothing wrong with being optimistic.

W I'm not going to sit here and say that he will forever be a failure, but my son you know he's a psychologist. He says mother you did such a big job on him everybody see the improvement in him. So he says what will come from the child is extra. It's extra. Also he's very seven year old. When he

W2 mischievous

W When I said you may not do that, now I have a top look on the door when nobody is there I put the top lock on he can never get out. He's fast and I sit here and I think. I have a lot of thinking all of the time. He think the door locked and then he comes back now I think I'm pretending I'm really sleeping and he crawls out. He so fast he thinks now she don't see me. He's stinker. He's really smarter than we all think. Because I took him in bed he was not well. I said come let's take a rest together. I lay up the side and he is lays and he didn't sleep at all. Let me give him a little Tylenol and we lay there together. He got up and got on his knee and crawled flat on his belly out of the room that I could not see him next to my bed. Now I call that a little stinker. More times when he will do something wrong and you pretend not seeing he watched you first. Now that's smart. So there is more than we can see.

MH I try to hold these conversations right around the hour marker because people get tired. Would there be anything that you would add to this conversation or information that you would share with families other professionals. This is your opportunity. I guarantee you that I will make sure your concerns are heard.

W Well the concerns are that social work will listen to us when we have a request and we want to talk or we ask questions that we should get answer and we don't. We don't. On the professionals I think that he could have more help then he's getting.

MH At the school?

W At the school for instances, yes. Also when you come with him to the doctor and he tip toes and you say well when we put that here he never been like this and you've got all kids of complications. I think the kids should be checked more thoroughly and more times and with more love not just on the door mate because that is a good belly that he has with a lot of muscles. That's a good looking boy. Where now is the cure to keep muscles that is in birth defect quiet certain experiences. How will I know? See what I mean. where are the solutions for the problems he has? Why don't you talk back to me when I ask them something? It takes me ten minutes to get the question out of them okay, but I get it out off the record I will tell you. Robert, Robert come here. Look at me nice. Look here, what color eyes do I have? Sit by mommy. Come baby, come. Look she wants to know what eyes do I have. No you have to look at me yeah, yeah. I have teeth too. You have teeth. Oh baby, but then he stand here and we laugh. We say teeth, then I say what eyes and he says blue, blue. I'm the only one with blue eyes in this household. He knows it's different alright, but he needs more that somebody else with him. That is how we have to do it and I don't want to wrestle him when he wants to say that I don't have blue eyes. you know what I mean. do I hold him and say you have to say you have to tell me? I don't think so. You know there are things that we can be instructed to do because it's very important that he look at me and at my face. I think that's very important, but sometimes we stand here yeah I have blue eyes and Robert have brown eyes. Robert have brown eyes. There must be a way that there is a way to get through. You know that and night too with the feet and legs a lot of noise, but he never practiced crying. Yeah, when he get hurt. When he stepped on a toy he get hurt. Toy's short.

MH He cries when he gets hurt.

W Yes, he cries when he gets hurt. He cries this week he sit with the fingers in the door. He closed the door but he couldn't get out either and I said oh he's stuck again because we are here. We never leave him alone, but that's the way he cries. When he stepped on the sharp part of a block he cried and I had to kiss it and then most of the time it's over. He can be away for four or five hours at night and he sings, he talks and that's it and hit the sides with his feet when he always move. That is his sickness. The singing you wouldn't believe it, how good he sings. He can hold a tune.

W2 Well he's in his own world right now.

MH I certainly want you to know how much we appreciate you sharing this.

W When we get any, any help we will take it with both hands. The more we can teach him believe me because a child like this you need special grapes and not met from the we will be the best to you because of what has been done to you. He has to understand that it is for his best and we love him. I think he does. I think he does. He's always glad the bus comes here. He's always glad the bus come back. You know he's overjoyed, but we need a lot of prayers and a lot of faith because it's a lot of work.

MH I'm going to think about Robert a little bit. I really haven't. My area is not Autistic like behavior my area is more communication, but

W Well he missed the communication.

MH I want to think of Robert. there may be some articles, some reading that might be real interesting to you and real useful. I'll have Anissa drop by and kinda share for you to get some more ideas that are in special education that deal with this a little bit more than I do and see if they can recommend some good material and some more information. I don't know anything about the school district here or services or provision. I'm really limited in that area, but I want to inquire a little bit. I think for what it's worth you guys are terrific. I'm just so impressed with the amount of training and the difference you've made and your energy and I think he's one lucky little boy to be placed with you.

W Yes, believe me I say amen to that

MH you tremendous person

W We love him to death

MH I would also say to you that probably there aren't answers to all of the questions that you have. I think in reality professionals don't know as much as they think they do. So

W2 You can't learn everything out of a book.

MH Exactly, I think

W2 I have my baby brother who is the doctor and sometimes I wonder what he learned out of the book.

MH I see it so much and I think a lot of things we just don't have answers for, but I also think

W We can love him a lot.

MH I also think that professionals could communicate that to families. Your doing a good job.

W Yeah, why don't they give us praise?

MH That's where I see the tragedy here.

W Once a year they could say

MH That the professionals that are working with you aren't reinforcing you for the good work and efforts that you are doing and admitting that there's a lot that they just don't know either. There's just a lot still with children like Robert that we just don't have all of the answers for.

W Also when you have workers that are brand new. Oh was he worse when he came and things like that.

MH Those are things of style that I'm working with my students a lot. sometimes if you have a style that is different from the family style it can be offensive and not mean to. So what I'm trying to do with my students is that there are a lot of different styles that you can use clinically and families expect. Some families want teaching, some just want support, nurturing. Some want education and training. Some want advocacy. So if students don't have all of that in their repertoire and they can pull that when they go to meet families. If I'm always the same then I'm not a human being one. I'm almost a robot. I think people need to realize that every situation is different and they need to identify that and not try to treat everything similarly and probably in our training programs we have it set up so that everything looks similar and it isn't. That's something that on the grant that the students learn about different cultures, different styles, different ethnicity, different
communities, different disabilities and Robert is a perfect case. You

Tape ended

W Now he swims by himself.

W2 Well it took two years to balance him out in that life jacket. then finally he outgrew the life jacket or it outgrew him. I'm not sure which way.

W Do we have the thing off?

MH We're gonna turn it off now.

Transcript of Structured Interview with African American Family

August 15, 1996

Mary Blake Huer, Ph.D., C.C.C., Moderator
California State University-Fullerton

Summary Background Information

Type of Group: Structured interview with two African American family members, Evelyn Hodge and Patricia Ray, who have a child in their home, Cameron, a 5-year, 7-month-old child who is reportedly a crack baby and who has Down syndrome. The family has no fixed strategy for identifying the child's communication needs.

Date Conducted: 8/15/96

Where Conducted: Family home in Watts district of Los Angeles

Logistical: Was unable to have family meet with information-gathering team outside the home. Considerable travel and prior preparations were required for team to go to home (e.g., use of cell phones to communicate with one another, conversations with persons in community regarding colors worn by local gangs to ensure that a 17-year-old team member serving as camera man would be dressed nonconspicuously and not become a target for aggressive behavior). Camera stopped during the interview and only audio was able to be captured.

Modifications: Deviated from protocol by allowing family to discuss tangential issues of concern to them. Was able to intermittently address issues related to AAC.

Synthesis Statements

1. Child Characteristics
   - Oldest child expected to be low functioning at birth but graduated at age 22
   - Oldest child speech was developed by time child was age 7
   - Family has no fixed strategy for identifying youngest child's communication needs

2. Family Perceptions of Professionals/Service System
   - Family pleased with support from professionals for oldest child
   - Family wants professionals to be patient
   - Family feels professionals should love their work with children

- Family wants al services that child is eligible to receive
- Professionals should be attentive to children's attention spans
- Family wants explanations of recommendations and choice in deciding whether to implement
- Family recognizes that professionals vary with regard to competency level

3. Family Goals/Aspirations
    - Child wants to learn to read
    - Family is unsure about child's potential for independence in future
    - Family would like child to be independent in an environment of his choice
    - Family wants community to see child as "worthy"
    - Child is accepted in African American community where everyone knows one another

4. Family & Stress
    - Family moderates stress with each successive child with a disability

Transcript

MH The purpose of these meetings is to talk about families that have children that have disabilities. The whole nature of it, especially families where there's a child where there's no speech- no communication. What we are trying to figure out is as a training program as people who prepare therapist from the families perspective how we could do more. How we could do a better job. How we could meet your needs. What you need from us, your experiences your frustrations. That's sorta what we want to talk about. There's really no list of set questions. There are some questions that I could ask if we all sit here silently and can't think of anything to say, but the real just of it is to get your guys opinion. To get your wisdom, your insight, your experiences about your children. That's the whole point of it. We'll talk about 30 to 45 minutes somewhere in there. More if we're still talking, but that's the nature. You guys can take turns, but that's really the point of it. My belief is that if I don't talk to the parents and I train someone to go and work with your child in the school or hospital or wherever and we don't include you that's not a very good strategy. So that's the whole purpose of this to reach out and get the families tell us, talk to us. How can we do better? What can we stop? What can we do more of? That sort of thing. So if you want to start by telling me just a little bit about your children, the nature of their disabilities, their history, how old they are. You were talking about before who they have been in speech therapy before. So if you kinda want to tell me a little bit about your children.

My name is Anita and I have a son that is Autistic. He had spinal meningitis when he was 2 1/2 years old and stayed in the hospital from 2 1/2 months until he was about 7 1/2 months and he had relapses of meningitis and that's why he's autistic now. The severity of his illness is from him being having meningitis at 2 1/2 months. He is multiple handicapped. He has behavior problems. He is hyperactive. He come a long ways because at the time when he was first diagnosed they thought he was going to be a vegetable and now he walks and will talk to you. He didn't start walking until he was about 3 1/2 or 4 years old. Speech came about 4 years maybe 5 just the single word speech. Seven and a-half is when he starts putting words together.

MH 71/2 years?

Seven and a-half. From the time he was 9 months until the time that he graduated at the age of 22 He has been in some type of school or program.

MH Is this his picture that I see up here.

Yes, that's Ronnie

MH So he's about 22 now?

No, he's 27.

MH 27 okay

He'll be 28 in September. At this present time he graduated from high school in 91. He been over to the Brentwood behavior center since then. They are about really to put him into a work program. He's doing very well compared to what he was when he was a boy because they really didn't think that he was going to be able to talk, walk or see. He was just gonna be a vegetable. So he's come a long ways.

MH And he has some speech now you said?

Oh he out talk anybody.

MH Really, that's been great.

From the time he gets up to the time he goes to bed.

MH Really, when he was a little boy before his speech came in sentences what kinds of things did they teach him or you try?

Well we used books, audiocassettes you know little stories different stuff like that. Mostly speech as school cause he did have speech everyday from the time he was about 7 till he was about 12 and then they said there was no use in Ronnie having speech cause his speech is better than everybody else. He used to speech real proper. He'd pronounce each word just properly.

MH So speech therapy was real successful. How about when you worked with the speech therapist. The professionals, did you feel like they worked nicely with you? Did you ever have questions? Did you feel included or excluded? Can you remember?

I didn't really work with the speech therapist at school. I did talk to them about what I should do. Like they said that if your are going to try to get a child to say a word, do say, "say a word" instead you say book. You don't say book. You say the word. Different ways to get them to speak and use balloons to put it up against the mouth so they can feel the vibration of the sounds of the words.

MH Wow you'd be a good speech therapist. We gonna have to get you in our program.

It's been so long I've forgot about half of the stuff that they used to do.

MH It sounds like you have a positive relationship with the therapist?

Oh yeah, ______ school was a really good school. Everybody worked together the speech therapist and the teachers at

MH They had regular meetings and they told you what was the goals were. Wow

IEPs yeah, If you into a good program where there's like a the regional centers they will let you know about everything. What's going and where to go to camp and just stuff like that. As soon as I got him I wrote into the regional center from the time he is in school until the time he graduates if there is anything I need they are supposed to supply it.

MH Really?

Yeah, so you just have to know where to go.

MH So tell me where did you learn where to go? Just kinda tell me. Word of mouth or the professionals?

I've been with the regional center since Ronnie was 7 years old.

MH So that's been about 20 years.

Yeah, about 20 years, I know just about everything. Where your supposed to go to find out all of the information and what programs that they have. After school programs. Like Ronnie right now he is at camp. They provide that.

MH How long have you had Cameron?

I've had Cameron since he was three days old.

MH He's about?

Cameron was born in 91. He is now 5 years and almost 7 months. Found out the he was a down syndrome child also a mother had used drugs, mostly cocaine from what I understand. So what I've found out about down syndrome is that they do have speech problems and that some of them may never speak and with the drugs and Cameron we won't know until he gets older how severe his handicaps is gonna be.

MH What kinds of things has the speech therapist done with him so far?

Right now Cameron is not with a speech therapist.

MH Okay

They use different things, techniques in the classroom and stuff like that. Simple sign language and stuff like that but he's not with a speech therapist.

MH Who teaches him the sign language? Did you?

Yeah, I learned it from Ronnie.

MH I can tell by your smile.

Well when he was in the Exceptional Children's Foundation they were using simple sign language- each, more bathroom, but I

MH You learned that for Ronnie and transferred that to Cameron.

Yeah

MH They didn't do that at the center yet at all? Interesting? Interesting?

Ronnie used to come home doing sign language and asked his teacher one day, Oh are you teaching Ronnie sign language when he was at Latchman High School and they say no he's just picked it up from us using it around children that's deaf. I say oh, okay I've learned a few.

MH So how many signs would Cameron have?

The only one that he does real good is more. The knows the sound when he hears me say bathroom and know he'll look at you and smile. He indicates that he knows what your talking about just by the look on his face when you say it.

MH There is a good chance that Cameron is gonna get into these videos. Is that okay with you?

I would want to make sure that we have your permission if he is on the video tape.

Say, I'm right in the middle of it now.

MH That's right. He's checking it out. He's listening. You can tell he's paying attention. Is getting on a little bit Jonathan? So you could get him. So how many signs would you say you've taught him so far?

Let's see bathroom, eat, more, no, yes, finish. What's that about six?

MH It sounds like the ones you just are real functional. Things that would be real meaningful and could kinda communicate. That's really what this study and what we do at Fullerton and it's really focusing on communication more than speech. There are a lot of kids. There's about 2 million that we are tracking trying to understand in the United States not like Cameron, but similar to Cameron in like they don't have the speech. They may be in wheelchairs. They may have cerebral palsy. That's what I do as a teacher is trying to prepare students to work with kids if there's not speech. There's a lot of other ways to communicate like you know. Cameron is full of communication he may not do the speech, so that's what we're trying to work on. What are your other options so that people don't get so nervous if there's no speech. To say there's sign. There's communication board. There's a little wallet, or book all kinds of things. We're trying to encourage persons to except those until the speech comes if it does and you never know.

Whatever helps and whatever works
MH So that's kinda the purpose of this

AJ I have a question. Anita up to this point has anyone offered any other type of communication or a different means so that you could tap into Cameron's way of communication? Did a speech therapist or someone at the Regional Center say did you think about this? Could we explore this like maybe a communication book so that you could have a functional way to communicate.

Not at this time.

MH Right know we're doing training and research. If we could get some space they'd give me a classroom space at Fullerton we hope to be able to do more clinic where we can talk to families and make suggestions about what the students are learning to help children like Cameron and other because there's so many in this LA area. Right know the room that we have is the size of a closet so you really can't get in there.

You can't really do anything

MH The students can hardly get in there so that's why we're real interested. Anissa been in there a lot of times.

Cameron that does not belong to you. Thank you

MH Other questions that we're interested in are when there's a breakdown in communication when you don't understand what he's saying how does it impact the rest of your family? Is it stressful do you problem solve? We're trying to get a sense of

Your trying to find out

MH We're trying to find out what you do and what you might need to do as the next step so that's what I'm supposed to ask.

Let the water go. Where did he find that?

MH Well he's competing for attention too.

Want to go in there with Tricia or June. No I don't want to see June.

MH I think he's okay. Cameron. If he seems frustrated and if he seems to want something and there's a breakdown what happens? How do you find out? How does that impact everybody?

I just talk to him and ask him what's wrong and see if I can figure out exactly what's going on with him. Like if he wants say he like to look at the words on the TV.

MH The words on the TV

You know the credits? He likes to look at the credits.

MH He wants to read.

You flip the TV and he's stand there and when and I'll look at him and say what's wrong? You want to look at the TV? I say TV. You want to see the words and he'll smile. I'll say you want the words and I'll put it back and he'll smile at me and so I'll know exactly it is. When he wants like something to drink he'll usually come if I have something in my hand. I'll drink something, give it to him and he'll drink it. There's no set way of me trying to find out what he want's.

MH Like he's been vocalizing a lot today.

Oh he does that everyday. He's good vocal.

MH If let's say Pat. How would Pat know if he's trying to talk or if he's just entertaining himself, what we call self stimulation. How would somebody know?

He would come up to you. He'll come up to you. Just like he did over here with Anissa. He came up to her then he backed off. Say now Cameron has problems with noises like when the house gets full over there cause you see how he was crying. About three or four weeks ago there was a house full of folks over here and everybody that would try to go to him; he would start crying. After a while if he's hasn't been around you. I'm surprised he's not crying now cause ya'll are strangers but at a certain level of noise will set him off. He'll go in the bedroom. He has a little mat and he lay on the mat or he'll sit and look at the TV until he calms down then he'll come in here and won't cry anymore. He has to get used to it.

MH So he can calm himself down. Wow

Oh yeah

MH Anissa said you have other children as well.

I have a daughter.

AJ It was my understanding that you had... did you have any other children that you worked with that had special needs or just the two?

Just the two that I really worked it

MH Now Pat your a sister?

Put it down.

MH I needed some more attention right there. I know if I pull this wire I get my mom's attention Can you tell me a little bit with you interactions with Cameron or if you guys communicate much or if you don't?

Normally if he wants something I don't thin I know what he want I ask Anita what he wants cause I know she know. I always tell her she's a god sent.

MH Your her tool.

That's right. I always tell her she's a god sent. It takes special people to have with special kids and she's special you know. So if it's something like I want to pick him up I'll say go pick up Cameron and brink him over. She'll get him and brink him to me or if I want to kiss him she bring him over to kiss me. He's that way with everybody if it's not her or her daughter, my sister's daughter older he doesn't warm up to you at all

not unless he gets used to you

Like Kamir was here that whole month. He was all over Kamir like white on rice. He seen her everyday, on an every day basis. Teko was here for almost month and they played and everything, but he has to get used to you.

MH How about these signs? Have you learned to sign language?

No

You don't know

Well she'll tell me, tell me to say more or talk to him a certain way that he'll know and not know. I don't know like she knows.

MH Your a very important lady.

To me she is anyway.

MH Let's see what some of these other things. Let's see they want me to talk a little bit about the future. If I ask you want are your expectations for Cameron in the future can you kinda talk about where you'd hope he'd go, or what you'll hope he'll be doing and when. Some things like that.

Now from what I understand with normal Downs children they can live normal lives. They can even work. They can live in independent home environments. With Cameron and his drug in his body when he was born I don't know how that's gonna affect him, but I hope that he can go as far as he can live independent and be able to work, be able to go to the store by himself. Stuff like that, but who knows like I said with the drugs in his body.

MH Do you know anything about the nature of the drugs?

She was using cocaine. She was smoking cocaine, crack.

MH So throughout the whole pregnancy you think?

From what I understand she told me she had almost virtually stopped smoking when she found out she was pregnant.

MH So right at the beginning maybe. What about in terms of his communication? What do you think? How many signs do you think he will learn or do you think the speech?

Between now and then he ought to know a whole lot because he's gonna have more speech. I'm gonna see to that from the time he leaves high school he's gonna be able to know how to communicate with somebody. Somebody is gonna put him somewhere.

MH Will you start doing some of the drills you learned for your son like the balloon and some of that

Yeah

MH You'll just start a program and work right through with him. You'll team him more signs?

Because like even if it comes to changing schools because I know that Lantrum has a school for the deaf, it is a school for the deaf and they have a good program over there.

MH Is it pretty easy for you to switch schools? Can you ask/request that he go to a different school?

I probably could

MH So you could?

Especially after he grows out of this school because I don't think that this school has a specific school for deaf children. It's different types of handicap, cerebral palsy, kids in wheelchairs, Downs all kinds of things.

MH Do you see those kids that are in wheelchairs or with cerebral palsy using sign or anything now at the school he's at?

Not in the classroom. Well, see there's different parts of the school. They have DCH. They have early education and then they have the regular school for the handicap and that's wheelchairs, walkers and braces and stuff, but don't have mental capacity where they can't learn. They're much faster so it's different stages of the school. It's not just a school for everybody. It goes from the early learning all the way up to the sixth grade so according to which type of handicap you have, how fast you learn that they put you in.

MH Have you been told anything about his mental ability? Do you have any ideas about anything how far you think he's gonna go?

I know it a ??year?? I do know. They can't tell how far he's gonna go. That's just like Ronnie. They could tell with Ronnie. They was predicting that Ronnie was gonna be a vegetable. Ronnie out walking, out talking everybody. He was supposed to be blind so you never know. They could say one thing and the whole thing is different when they get older. Put the wire down Cameron Daniel. Cameron look at me. You hear me put the wire down. Let the wire go. I see you looking at me sideways. You wanta play with that wire with you toes.

MH He's okay

You want to play with that wire with you toes. Give me this.

MH Let's see another thing that we're interested in is the child is not at school

He better be sick

MH and when the child is not in your home

They only reason they stay home.

MH In terms of if you take Cameron or when you took Ronnie into the community like social activities like if they go to church or with relatives. When they're out of your home or school at a park or whatever they want us to find out about concerns, frustrations, successes. Can you speak a little bit about if you take Cameron outside for a walk or if he's ever out of the home and not at school. Is he out of the home and not at school sometimes?

Yeah, he goes outside. We go to the doctor or walk in the neighborhood.

MH So how about when your walking in the neighborhood are there any concerns you have? How do people in the neighborhood react to him? They are trying to get a sense of

Well everybody around here known each other for over 20 years.

MH Really, so

We grew up on this corner.

MH So people are pretty familiar with each other.

This neighborhood, yeah

MH So they've watched him grow up since he was little.

Everybody ask me how 's Cameron doing? How's Ronnie doing? They always ask me him. They speak with him when he's outside on the porch or in the yard. You've got somebody's keys.

MH How do they speak with him?

They just talk to him

MH Does he relate to them?

Yeah, he'll look up and smile at them or make sounds at them like he's trying to communicate with them. Cameron stop gritting your teeth. Do you like those keys?

MH How about you Pat what kinda of expectations do you have for Cameron or what kind of involvement do you see yourself in the future?

I would like for him to live as normal as possibly could be for him and be on his own and be in an environment of his own, be able to communicate with others and just have some form of a life. To not be looked at as not worthy.

MH Do you get a sense that your other family members or neighbors or people don't except him or do?

No, no not around here. We've been here since I was 12 and I'm 44. I'm the youngest so everybody, the neighborhood hasn't changed much from blocks over. From blocks that way and blocks this way so in the immediate area no from who we socialize with or who we deal with on a day to day basis. Then you have some kids who don't know

Kids can be very cruel

Kids are the most cruel of all because they don't know cause then you have to relate back to their parents cause their parents don't teach them. See cause I always say special to me these kids are special. My sister might say handicap. She might say Autistic, but I always say special. I think that

Get you paper, get your paper

MH Are you going to eat my paper Cameron? Let me have it

Yes, he like paper.

MH So I guess he'll take it here

Let mama have the paper. Give mama the papers. Thank you.

MH Let me see if there's a page that I don't need anymore.
I wish society could learn more about special kids and be able to teach their kids about special kids so they don't grow up thinking that because they don't walk, talk and appear as we do that they are less then we are or something wrong or you can't touch them you know.

MH Do you think that neighbors feel pretty comfortable then?

Oh yeah

MH Cameron how about all these. There's a staple right there. He can have all those pages he can just do whatever.

He can really tear up paper.

MH You might give him a page at a time. That staple might rip his finger. There you go guy you can have some paper. Yeah, those are for you.

Thank you. Cameron

MH He says I'm busy

Cameron say thank you. He like the way the noise is sounding.

MH He likes the noise that makes? Interesting. Let's see how about advice. This is your opportunity to give some professionals advice. If you could tell professionals what they need to do to help you and other families with special kids what kinds of advice would you offer? Say it's a brand new family for the first time

AJ What kind of advice would you give to me. I'm going to be brand new working with kids just like Cameron.

MH Yeah, What would you tell Anissa?

Oh lord, have a lot patience. Be special like she is. I don't know.

What your gonna do and what you wanta get into. You have to love it. You have to love it to stay in it. It can get hectic so you have to love it.

AJ What kind of skill you want me like if I came into your house and I said okay Anita we're gonna work with Cameron. What kind of skills do you want me to have? Do you want me to just be able to work with his speech or do you want total communication? What are you looking for out of a therapist?

Well total communication would be good if that what your into, but if it's just speech. It has to be whatever your doing all over. If you do it all over then that's what I want. I want it all. If you just doing a segment or part of it. When they came and gave him physical therapy that was all that she did was physical therapy.

MH How about stress?

Stress

MH We're supposed to talk about stress.

Everybody got stress just different kinds that all

MH Like um I think a lot of times professionals one they probably don't have kids you know and they come with a list and say we want you to do this, this and this. So we're trying to get a sense that professionals have a sense of how much time special kids take, the kind so of stress special kids might take, the stresses families might feel cause they've got kids that might be doing different things with. Can you give some examples or think of some things that might be meaningful for new clinicians like Anissa to just know about time constraints and stresses.

Handicap children- their attention span is very short so you can't stay on the same thing for a very long amount of time. Say like you well I'm trying to get him to go to the bathroom and I know he's not going to sit on the potty for a long period of time without him fidgeting and getting mad so I put him on there a few minutes as a time and then come back and try it again. You have to do that with all handicap because if you keep trying to get them to do the same thing, the same thing, the same thing like Ronnie he'll go off. He'll get pissed off and start yelling and screaming so you just have to know what's the limits to each person your working with.

So what does Cameron do, Anita when he don't want to do something?

He'll cry.

That's all

He'll cry that all. I've seen Ronnie go through a thing where he didn't want to do something.

Right and try to go off

right, right

You stop him. Yeah you usually have to stop him right then and there cause if you don't catch him right then and there you just run on and go crazy. So you have to catch him at that point, but before you get to that point your supposed to stop. I've learned that cause little minds is gonna only take so much in and then once it get on one little thing, it's on that. Like Ronnie he doesn't like you telling him no you can't do this. No you can't do that or no you can't have this. When he gets crazy on me I let him go into his room. Time to go to your room and close the door or I'll close my door. He gotten to the place if he finds my door closed and if I'm laying in the bed sleeping he won't come in there. He'll peek in and see if I'm in the bed cause he's gonna go back in his room with the TV, but see he's learned that. Like he had to learn when I went back to work. Every when the day, I work part-time. The days I work every time I went to work

Ronnie threw a fit. So he had to learn. I had to tell him, Ronnie a couple of days before. Ronnie I have to go to work on Saturday so you have to be cool. Now it doesn't bother him. He go in his room 6 o'clock in the morning I walking out the door he's laying in bed until the van comes to pick him up. At 7:30 Cameron is getting on the bus and Ronnie is sitting on the couch waiting on his van. He don't fuss like he used to. They used to have to call me mama Ronnie is throwing a fit. Put him on the phone. You better stop that mess you know I have to come to work. I've had the school call me. I say put Ronnie on the phone. I'd say you better stop all that mess. She ask what did you say. I just told him he better stop the mess. She just said okay.

My kids aren't' handicap and they'll hang up the phone. Okay mom and go back to what they were doing.

I deal better with Ronnie and Cameron then some of these kids that are supposed to be normal. I'm serious. At least I know with my kids they ain't gang banging and shooting folks.

You know that you always in control

So I don't have to think about that, but you can get stress out. Like if I get stressed out I have to rest for a while. I just go to the regional center and send the kids to respite.

She don't' do that. Ask her the last time the kids have been to respite.

MH Probably a year, right.

Longer than a year

I make her take vacations with us. You need to say your money we're going to so and so. Ain't no kids allowed just us Anita. Okay, Nita we're going to so and so, cause other wise she would never get a rest. I always say she's special.

MH I can see that

She is. She truly is. I grew up with her.

It's like second nature for me. It's not like somebody getting into for the first time. I've been it for 20 years, it's like second nature. It don't bother me as much as it did when I first started when I was 19 and found out that Ronnie was handicap. I had a whole lot of stress. What am I gonna do? Where I'm gonna go? What's gonna happen? What he gonna be? Now I know and like Cameron, if I want something I know exactly where to call so I don't have to worry about all that stress because I've been in it so long

They just can tell you anything know.

Right

MH Last question what do you do if you have a clinician, teacher or so professional and their beliefs are different from yours how do you handle it? Let's say you have some lady with a clip board and comes in and gives you a list of things to do. A lot of professionals are kinda pushy so how do you handle if there's a difference in beliefs?

Short break

So what were you saying?

How do you handle a professional who has a different set of beliefs then yours?

As far as the special kids go?

MH As far as your interaction with professionals. Let's say I came in with a clip board and I said there's 10 things you need to do.

First you would have to tell me why I need to do this and what's the purpose of it and then if I feel that it would benefit one of the children that I have fine I'll do it.

And if you don't then what do you do?

I'd have to tell her thank you but I will try it but if it doesn't work it's gone.

MH But you will at least try it, but my I think that

You know what I've found over the years there are more good therapist and teachers then there are bad. Very seldom do you run into someone who thinks they know more than you because people that I have been with and around has always interacted with the families so they have dealt with the families a lot and so you don't find a lot of conflict.

MH Cause in some areas, in some schools we find parents who are unhappy and frustrated.

See you find it in the schools

MH And they're not getting the services.

Right, then they are looking for something they can probably never have or in some form of denial. Like the doctor told me Ronnie will never be president, but he will be able to recognize and do things that he will be able to do, but Ronnie will never be able to read. There's certain words that Ronnie knows just by looking at when he sees them, but he can't write unless you hold his hand. He knows his name when he sees it. He knows different colors when he see them both the color and written. So who knows.

What would you like to tell a future group of professionals and then we'll turn off.

I don't know. Communication that's the best thing.

Revised Focus Group Protocol (For All Groups)

Before participants arrive: Ask participants to bring photos of their children using their AAC devices with family members or in the community. This will need to be requested via telephone or through written communication, with consent forms being secured. We will need their permission to use these photos in the CD-ROM. Other persons who are not involved in the Focus Groups can also contribute photos. Check audiocassette recorder before participants arrive to ensure that the appropriate volume level is set; check the volume level by recording your own voice in a conversational mode while seated in a chair that a participant will be occupying

1. **Welcome everyone**
2. **Describe the purpose of the focus group interview:**

   Example: "The purpose of this group coming together today is to discuss issues about augmentative and alternative communication (AAC) devices and how they affect families of children with disabilities. For the purposes of this discussion, AAC devices are defined simply as "voice output communication aides which require training to use efficiently. These include devices such as ________, ___________, and _______ (provide examples relevant to the focus group participants that you are working with)."

   (For family members say), "Each of you has been asked to be here today because you have a child who will have (or who uses) and AAC device. You have experiences in working with professionals during the AAC assessment process. You may also have your own personal insights, feelings, and experiences with AAC devices that are important for those of us trying to understand how these devices affect families."

   (For vendors and related services personnel say), "Each of you has been asked to be here today because you have had experiences in working with families and other professionals in providing AAC devices to children with disabilities. You may also have your own personal insights, feelings, and experiences regarding the process of providing AAC devices that are important for those of us trying to understand how these devices affect families.

Then say, "I will help guide the discussion that we have today and will be presenting a series of questions for you to think about and comment on as a group. Again, the focus of our discussions will be on the impact of AAC devices on families. Remember, your thoughts and concerns will be used to develop training materials that will be used to help families, professionals, vendors, and others who are involved in AAC decision-making around the country. Consequently, we will be using a camera and microphones to capture our discussion so that it can be used later.

3. **Review and collect consent forms and demographic forms** (this may be done in advance for some groups). Also, any still photographs of family members and children using AAC devices in real life settings should be collected with appropriate releases for use of materials (you may have to contact families in advance for these photos which can be returned as soon as they are scanned; photos will be used for collages and other creative ways when developing the CD-ROM).
4. **Explain how the group will proceed**

- First, we will talk about the ground rules for the focus groups.
- Then we will ask for introductions on tape and take some pictures of you that may be used later on when we develop the training materials. This will also give us the opportunity to check out our equipment. (At this point, still pictures and/or video footage of participants may be taken using the guidelines provided by Alan VanBiervliet in *Notes on Recording Video for Digital Images*). Remember:
  - use a high quality S-VHS camera if possible; two cameras would be desirable to provide a range of quality video shots; cameras used for long shots should be securely mounted on tripods, while a hand-held camera may be used for zoom shots and human interest images

- Be familiar with general camera techniques (pp. 3-4, *Notes on Recording Video for Digital Images*)
- use what you know about taking a good snapshot for composing pictures for the still photos
- Be sure you know how to turn off any features that automatically prints info like a time or date on the video (DO NOT RECORD ANY TEXT ON THE VIDEO).
- Be sure that you are using a microphone which can record the very highest quality sound that is possible for your particular situation. A PZM mike will probably be best (see p. 5, *Notes on Recording Video for Digital Images*). If you do not have access to a PZM mike, please contact the Principal Investigator and he will make arrangements to purchase one and forward to you for use at your site/s.
- Remember lighting concerns (see p. 5, *Notes on Recording Video for Digital Images*); you should check in advance to be sure that adequate lighting is available enabling you to shoot bright details.

- Then say, "I will then ask some initial questions and all participants will join in with responses and other questions. You may agree or disagree with any statement that is made. All opinions by group participants will be respected. We will be recording your participation using both a video camera and tape recorder. "

5. Explain the role of the observer (camera/sound personnel)

- arrange seating and draw seating chart to accommodate video/audio capture
- explain the role/s of the camera/sound personnel
- pass out name tags
- record group dynamics

6. Review the ground rules

- we would like to hear from everyone
- This is an open conversation and you can ask questions and respond to each other
- There are no right and wrong answers

- You are the experts

7. **Turn on the tape recorder and ask each person to introduce themselves**
8. **Ask the first question and choose someone to start** (see attachment for questions for specific groups); continue with responses and other questions
9. **Ask second question.** Bring in all persons (e.g., "Bob, what do you think about that?")
10. **Before closing, ask if there are any other questions they have or want addressed**. ("Do any of you have anything else that you want to say?").

    Member checks: Then identify ask participants if anyone would be willing to participate in a follow-up contact by phone call several months later. The purpose of this phone call will be to conduct a "member check" to verify the issues identified by the group. We will simply identify the major issues which were discussed by the focus group participants and the members will us feedback regarding the accuracy of our statements. Get the names and phone numbers of 2-3 participants per group willing to participate, and identify an appropriate time that is best to call for the member check.
11. **Thank everyone for coming and participating in the group.**
12. **Conduct debriefing immediately and write down impressions and reactions (it is important to make oral notes directly on the tape at this point in time).**

Specific Questions for Family Protocol:

1. **For families who have not received devices yet:** What are your goals or expectations for the AAC device that your child will receive?

   For families who have already received devices: What were your goals or expectations for your child's AAC device before it was received ?

2. **For families who have already received devices:** Have your goals or expectations about the potential of the AAC device changed since your child has been using the device? Describe in what ways they have changed.

3. Let's explore in what ways, if any, an AAC device might affect or has affected your family?

   Probe questions depending on number of responses offered by group:

- Do you see it affecting (or has it affected) roles that you must assume?
- Do you think it would affect organization of the home environment?
- Do you think it would affect relationships with family members?
- Do you think it would affect demands placed on your time?
- Do you think it would affect levels of stress which you currently experience?
- Do you think it would affect your relationship with others, particularly in the community?
- Do you think it would affect your ability to take your child into the community, to eat at restaurants, or other social or recreational activities?

4. What have been your greatest concerns in working with professionals in getting your child's AAC device?

5. What should the role of professionals be when trying to work with you to get your child an AAC device?

6. What things about AAC devices that were important to you were **not** considered by professionals?

7. If you could tell professionals how to better work with families when trying to identify AAC devices for children, what would you say?

8. How, if at all, are the values and beliefs of professionals different from yours? If so, how

did these differences affect what happened when decisions were being made about AAC devices?

9. Is there anything else about this subject that I haven't asked you about?

Specific Questions for Professional (Vendor, Related Service, and Multicultural) Groups:

1. What do you perceive the goals or expectations to be for families and children who want AAC devices but have not received them? Do you think that their goals or expectations change after they have received AAC devices? In what ways?
2. In what ways, if any, do you think an AAC device positively affects families? Do you think there are any negative impacts of AAC devices?

Specific probe questions depending on number of responses offered by group:

- Do you think it would affect roles that family members must assume?
- Do you think it would affect organization of the home environment?
- Do you think it would affect relationships with family members?
- Do you think it would affect demands placed on your time?
- Do you think it would affect levels of stress which you currently experience?
- Do you think it would affect the relationship that family members have with others, particularly in the community?
- Do you think it would affect the family's ability to take their child into the community, to eat at restaurants, or other social or recreational activities?

3. Describe the greatest concerns you've encountered in working with families during AAC decision-making?
4. Describe the roles of family members during AAC decision-making processes?
5. Describe things about AAC devices that tend not to be considered by family members?
6. What advice could you offer family members on how to better work with professionals when trying to identify AAC devices for children?
7. Do you think that the values and beliefs of families are different from yours? If so, how did these differences affect what happened when decisions were being made about AAC devices?
8. What changes are needed in AAC decision-making processes to make it easier to work with

families?

9. Think of a time when you have worked very well with a family and a time when you didn't. Can you describe what was different for these families and for you?
10. Is there anything else about this subject that I haven't asked you about?

General Information Form

1. Circle the **highest grade you have completed** in school.
   1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 20+

2. When is your **birthdate**? _______ _______ _______
   month day year

3. What is your current **marital status**? (Circle one)

Married...........	1	Separated...........	3	Live-In Partner......	5
Divorced.........	2	Widowed...........	4	Never Married......	6

4. What is your **ethnic origin**? (Circle one and elaborate if desired)

Asian American...	1	Hispanic American...	3	Euro American........	5
____________		____________		____________	
African American.....	2	Native American......	4	Other..........................	6
____________		____________		____________	

6. What is your current **employment status**? (Circle all that apply)

Employed Part-Time..................	1	Unemployed..........................	5
Employed Full-Time..................	2	Part-Time Student....................	6
On Disability Status..................	3	Full-Time Student....................	7
Full-time Homemaker...............	4		

7. Which of the following **socioeconomic class groups** is representative of you or your family?

$0 to $4,999.........................	1	$20,000 to 39,999.................	5
$5,000 to $9,999....................	2	$40,000 to 59,000.................	6
$10,000 to $14,999................	3	Over $60,000.......................	7
$15,000 to $19,999................	4		

8. **If you are a family member with a child having a disability**, please provide the following information concerning the child in your home who is using an AAC device.
   Age of child:___________
   Diagnosed disability:______________________
   Please list the AAC device(s) that you or your child:
   is currently considering______________________________
   is currently using____________________________________
   have used in the past________________________________

Desired Services

In consulting with educational and related services personnel in your service system (early intervention or school district), what types of services would you find helpful in assisting your family with AAC devices? Check (√) all that apply.

___ Provide information about laws governing the use of AAC devices at school

___ Assistance in learning to play an active role in the educational process (assessments, IEP meetings, etc.)

___ Liaison between staff, parents and agencies

___ Parent training (communication and problem-solving skills)

___ Range of AAC devices available

___ Financial resources for purchase of AAC devices

___ Lending programs for AAC devices

___ Places to go to try out AAC devices

___ Network of parents who have used various AAC devices

___ Support group for parents of children who use AAC devices

___ Identification of training programs for use and maintanence of AAC devices

___ Strategies for coping with stress

___ Helping siblings cope with stress

___ Other (please list or describe additional services):

Code No: ________

Assessment Form: AAC Impact: Families Waiting for Devices

This questionnaire is designed to understand how AAC devices affect families. AAC devices are defined simply as “voice output communication aides which require training to use efficiently”. It will not take much time to complete. Each set of questions will be introduced by several statements. You should **check** (√) either **YES**, **NO**, or **SOMETIMES** in the appropriate column after each question. You will also be asked to provide specific information about your thoughts, feelings, or experiences when answering some questions. *Thank you for your time and participation.*

Goals and expectations in using the AAC device. Family members and children may have goals or expectations before and after receiving AAC devices. These goals or expectations may or may not change once devices are actually received and used by the child and family. Think about the goals and expectations that you have for your child and his or her AAC device. Then answer the following questions:

1. Do you have goals or expectations for your child related to use of an AAC device even though your child has not received it yet?
   If **YES** or **SOMETIMES**, what are your goals or expectations?

YES	NO	Sometimes

2. Do you think your goals or expectations for your child might change once you receive the AAC device?
   If **YES** or **SOMETIMES**, in what ways do you think they might change?

Training in the use of the AAC device. As with any new electronic device, family members and children must often learn to use AAC devices appropriately. Sometimes training is required to use the AAC device. There may be **concerns** (**negative effects**) that result from *receiving* or *not receiving* training. There may also be **positive effects** that result from *receiving* or *not receiving* training. Think about both the positive and negative effects that might result from *receiving* or *not receiving* training, and then answer the following questions:

3. If you **receive training** to learn how to use or maintain your child's AAC device, are there any **concerns** that you expect to have prior to, during, or after the training?

YES	NO	Sometimes

If **YES** or **SOMETIMES,** what specific **concerns** might you have prior to, during, or after the training?

4. If you **receive training** to learn how to use or maintain your child's AAC device, are there **positive effects** that you might expect prior to, during, or after the training was provided?

If **YES** or **SOMETIMES,** what do you think these **positive effects** might be prior to, during, or after the training?

5. If you **do not receive training** to learn how to use or maintain your child's AAC device, are there any **concerns** that you think you might have prior to or after receiving the AAC device?

If **YES** or **SOMETIMES,** what specific **concerns** might you have prior to or after receiving the device?

6. If you **do not receive training** to learn how to use or maintain your child's AAC device, are there **positive effects** that you think might expect prior to or after receiving the device?

If **YES** or **SOMETIMES,** what **positive effects** might you expect prior to or after receiving the device?

7. If you have **already received some training** in the use of the AAC device, might this **additional training** have any effects on your child or family?

If **YES** or **SOMETIMES,** how might the **additional training** affect your child or family?

If **NO,** why would the **additional training not** affect your child or family?

Home responsibilities. Using AAC devices in the home may or may not affect the responsibilities of family members. Think about your child's AAC device and how it might affect your family responsibilities and routines. Then answer the following questions:

8. Do you think that you will have to take time daily to help your child use or maintain the AAC device?

YES	NO	Sometimes

If **YES** or **SOMETIMES**, how much time (on the average)?
________ minutes __________ hours

9. Do you think your child's AAC device will place demands on the family?

If **YES** or **SOMETIMES**, how might these demands affect the family?

10. Do you think that your child's AAC device will require changes in the home environment (e.g., rules, moving furniture)?

If **YES** or **SOMETIMES**, what changes might need to be made?

Family issues. Sometimes AAC devices used by a child will affect family members in the ways they behave toward one another. Think about ways in which your child's AAC device might affect the family as a whole. Then respond to the following questions:

11. Do you think that helping your child use or maintain his or her AAC device might affect other children in the family?

If **YES** or **SOMETIMES**, how might other children be affected?

12. Do you think that your spouse or significant other might be affected by the amount of time your spend using or maintaining the child's AAC device?

If **YES** or **SOMETIMES**, in what ways might he or she be affected?

Personal issues. Family members sometimes are affected personally when an AAC device is used by their child. Think about your child's AAC device and whether it might have an effect on a family member. Then answer the following questions:

13. Do you think you will use your child's device during social or recreational activities (e.g., going to restaurants, in church, etc.)?

    If **YES** or **SOMETIMES**, might this have an effect on your family's quality of life?

YES	NO	Sometimes

If it **might have an effect on the quality of life**, please describe how:

If you **do not think you will use your child's AAC device in social or recreational activities**, what might be the reason?

14. Do you think that use or maintenance of your child's AAC device might change the way that you feel about yourself?

If **YES** or **SOMETIMES**, in what ways do you think you might feel differently?

15. Do you think that use or maintenance of your child's AAC device might change the way that you feel about others in the family?

If **YES** or **SOMETIMES**, in what ways might you feel differently about the family (please describe):

Outside the home. Using AAC devices in the community (e.g., at the store, when visiting friends) may sometimes have an affect on the family. Think about the ways in which you and your child might use the AAC device in community settings. Then answer the following questions:

16. Do you think you might have concerns about your child's AAC device use in the community?

If **YES** or **SOMETIMES**, what specific concerns might you have?

17. Do you think that use or maintenance of your child's AAC device might change the way that people in the community feel about you?

YES	NO	Sometimes

If **YES** or **SOMETIMES**, in what ways might they feel differently?

Working with professionals. In order to get a child's AAC device, family members have to work with one or more professionals. This may have been during assessment for or training in the use of the AAC device. Family members often have differing experiences in working with professionals. Think about your experiences with professionals. Then answer the following questions.

18. Do you think that professionals who work with you to get a child's AAC device understand your needs and concerns about the device?

If **NO** or **SOMETIMES**, in what ways might professionals not understand your needs?

If **YES**, in what ways might they demonstrate an understanding of your needs?

19. Do you think that professionals who work with you to get your child's AAC device value and respect you as a member of the team?

If **NO** or **SOMETIMES**, in what ways do you feel that they might not value your participation?

If **YES**, in what ways do you feel that they might value your participation as team members?

20. Have your experiences with professionals changed the way that you feel about professionals who work with family members?

If **YES** or **SOMETIMES**, in what ways do you see professionals differently?

Code No: ________

AAC Impact: Families Waiting for Devices

This questionnaire is designed to understand how AAC devices affect families. AAC devices are defined simply as "voice output communication aides which require training to use efficiently". It will not take much time to complete. Each set of questions will be introduced by several statements. You should **check** (√) either **YES**, **NO**, or **SOMETIMES** in the appropriate column after each question. You will also be asked to provide specific information about your thoughts, feelings, or experiences when answering some questions. *Thank you for your time and participation.*

Goals and expectations in using the AAC device. Family members and children may have goals or expectations before and after receiving AAC devices. These goals or expectations may or may not change once devices are actually received and used by the child and family. Think about the goals and expectations that you have for your child and his or her AAC device. Then answer the following questions:

1. Do you have goals or expectations for your child related to use of an AAC device even though your child has not received it yet?

YES	NO	Sometimes

If **YES** or **SOMETIMES**, what are your goals or expectations?

2. Do you think your goals or expectations for your child might change once you receive the AAC device?

If **YES** or **SOMETIMES**, in what ways do you think they might change?

Training in the use of the AAC device. As with any new electronic device, family members and children must often learn to use AAC devices appropriately. Sometimes training is required to use the AAC device. There may be **concerns** (**negative effects**) that result from *receiving* or *not receiving* training. There may also be **positive effects** that result from *receiving* or *not receiving* training. Think about both the positive and negative effects that might result from *receiving* or *not receiving* training, and then answer the following questions:

YES	NO	Sometimes

3. If you **receive training** to learn how to use or maintain your child's AAC device, are there any **concerns** that you expect to have prior to, during, or after the training?
If **YES** or **SOMETIMES,** what specific **concerns** might you have prior to, during, or after the training?

4. If you **receive training** to learn how to use or maintain your child's AAC device, are there **positive effects** that you might expect prior to, during, or after the training was provided?
If **YES** or **SOMETIMES,** what do you think these **positive effects** might be prior to, during, or after the training?

5. If you **do not receive training** to learn how to use or maintain your child's AAC device, are there any **concerns** that you think you might have prior to or after receiving the AAC device?
If **YES** or **SOMETIMES,** what specific **concerns** might you have prior to or after receiving the device?

6. If you **do not receive training** to learn how to use or maintain your child's AAC device, are there **positive effects** that you think might expect prior to or after receiving the device?
If **YES** or **SOMETIMES,** what **positive effects** might you expect prior to or after receiving the device?

7. If you have **already received some training** in the use of the AAC device, might this **additional training** have any effects on your child or family?
If **YES** or **SOMETIMES,** how might the **additional training** affect your child or family?

If **NO,** why would the **additional training not** affect your child or family?

Home responsibilities. Using AAC devices in the home may or may not affect the responsibilities of family members. Think about your child's AAC device and how it might affect your family responsibilities and routines. Then answer the following questions:

8. Do you think that you will have to take time daily to help your child use or maintain the AAC device?

YES	NO	Sometimes

If **YES** or **SOMETIMES**, how much time (on the average)?
_________ minutes __________ hours

9. Do you think your child's AAC device will place demands on the family?

If **YES** or **SOMETIMES**, how might these demands affect the family?

10. Do you think that your child's AAC device will require changes in the home environment (e.g., rules, moving furniture)?

If **YES** or **SOMETIMES**, what changes might need to be made?

Family issues. Sometimes AAC devices used by a child will affect family members in the ways they behave toward one another. Think about ways in which your child's AAC device might affect the family as a whole. Then respond to the following questions:

11. Do you think that helping your child use or maintain his or her AAC device might affect other children in the family?

If **YES** or **SOMETIMES**, how might other children be affected?

12. Do you think that your spouse or significant other might be affected by the amount of time your spend using or maintaining the child's AAC device?

If **YES** or **SOMETIMES**, in what ways might he or she be affected?

Personal issues. Family members sometimes are affected personally when an AAC device is used by their child. Think about your child's AAC device and whether it might have an effect on a family member. Then answer the following questions:

YES	NO	Sometimes

13. Do you think you will use your child's device during social or recreational activities (e.g., going to restaurants, in church, etc.)?

    If **YES** or **SOMETIMES**, might this have an effect on your family's quality of life?

    If it **might have an effect on the quality of life**, please describe how:

    If you **do not think you will use your child's AAC device in social or recreational activities**, what might be the reason?

14. Do you think that use or maintenance of your child's AAC device might change the way that you feel about yourself?

    If **YES** or **SOMETIMES**, in what ways do you think you might feel differently?

15. Do you think that use or maintenance of your child's AAC device might change the way that you feel about others in the family?

    If **YES** or **SOMETIMES**, in what ways might you feel differently about the family (please describe):

Outside the home. Using AAC devices in the community (e.g., at the store, when visiting friends) may sometimes have an affect on the family. Think about the ways in which you and your child might use the AAC device in community settings. Then answer the following questions:

16. Do you think you might have concerns about your child's AAC device use in the community?

    If **YES** or **SOMETIMES**, what specific concerns might you have?

17. Do you think that use or maintenance of your child's AAC device might change the way that people in the community feel about you?
If **YES** or **SOMETIMES**, in what ways might they feel differently?

YES	NO	Sometimes

Working with professionals. In order to get a child's AAC device, family members have to work with one or more professionals. This may have been during assessment for or training in the use of the AAC device. Family members often have differing experiences in working with professionals. Think about your experiences with professionals. Then answer the following questions.

18. Do you think that professionals who work with you to get a child's AAC device understand your needs and concerns about the device?
If **NO** or **SOMETIMES**, in what ways might professionals not understand your needs?

If **YES**, in what ways might they demonstrate an understanding of your needs?

19. Do you think that professionals who work with you to get your child's AAC device value and respect you as a member of the team?
If **NO** or **SOMETIMES**, in what ways do you feel that they might not value your participation?

If **YES**, in what ways do you feel that they might value your participation as team members?

20. Have your experiences with professionals changed the way that you feel about professionals who work with family members?
If **YES** or **SOMETIMES**, in what ways do you see professionals differently?

Code No: ________

AAC Impact: Related Services Personnel

This questionnaire is designed to identify ways in which electronic AAC devices (e.g, Liberator, TouchTalker, IntroTalker, etc.) affect families. It will only take a few minutes to complete. Please answer the first few questions in the space provided. Then **check** (√) either **YES**, **NO**, or **SOMETIMES** after the next group of questions. *Thank you for your time and participation.*

Question	**YES**	**NO**	**Some-times**	**Don't Know**
1. Do family members that you work with have to receive training to learn how to use or maintain their children's AAC devices?				
If **YES** or **SOMETIMES**, does this result in family concerns (e.g., difficulty in finding child care, change in your family routine, transportation, or other disruptions) If **YES** or **SOMETIMES**, what specific changes have you observed?				
2. Do family members have to take time daily to help their children use or maintain their AAC devices? If **YES** or **SOMETIMES**, how much time (on the average) _________ minutes __________ hours				
3. Do family members for whom you have prescribed AAC devices use them during social or recreational activities (e.g., going to restaurants, in church, etc.)?				
If **YES** or **SOMETIMES**, does this result in any concerns that are expressed by family members (e.g., difficulty in finding child care, change in your family routine, or other disruptions) If **YES** or **SOMETIMES**, what specific concerns have family members expressed about AAC use in social or recreational settings? (please list)				
4. Do you think that AAC devices place demands on family members? If **YES** or **SOMETIMES**, what specific demands do you think may affect family functioning (please list):				

Question	YES	NO	Some-times	Don't Know
5. Do you think that AAC devices requires changes in the home environment of families (e.g., rules, moving furniture)? If **YES** or **SOMETIMES**, what changes do you think must be made (please list):				
6. When family members mus help a child use or maintain his or her AAC device, does this cause concerns for other children in the family (e.g, jealousy, anger, desire to be involved with device usage)? If **YES** or **SOMETIMES**, what concerns have been expressed to you (please list):				
7. Does the amount of time that a family member spend using or maintaining a child's AAC device cause concerns for the spouse or significant other? If **YES** or **SOMETIMES**, what concerns have been communicated to you (please list):				
8. Do family members have concerns about their child's AAC device use outside the home? If **YES** or **SOMETIMES**, what concerns have you observed (please list):				
9. Do family members feel that they need additional training to be able to more effectively use their child's AAC device?				
If **YES** or **SOMETIMES**, do you think that the service system (early intervention program or school system is typically able to provide the necessary training?				
10. Do changes occur in the family routines of family members if they receive additional training in the use of their children's AAC device? If **YES** or **SOMETIMES**, what changes would you expect (please list):				

Question	YES	NO	Sometimes	Don't Know
11. Does family use or maintenance of their children's AAC device change the way that family members feel about themselves? If **YES** or **SOMETIMES**, in what ways does it change the way they feel (please list):				
12. Does family use or maintenance of their children's AAC device change the way that they about others in the family? If **YES** or **SOMETIMES**, in what ways does it change the way they feel (please list):				
13. Does family use or maintenance of their children's AAC device change the way that they feel about early intervention professionals or school personnel? If **YES** or **SOMETIMES**, in what ways does it change the way they feel (please list):				
14. Does family use or maintenance of their children's AAC device change the way that people in the community feel about them? If **YES** or **SOMETIMES**, in what ways does it change the way they feel (please list):				
15. Do family goals change once family members receive their child's AAC device?				
Do family members have higher goals or expectations for their child after receiving an AAC device? If **YES** or **SOMETIMES**, in what ways are they higher (please list):				
16. Do family members have lower goals or expectations for their child after receiving an AAC device? If **YES** or **SOMETIMES**, in what ways are they lower (please list):				

Question	**YES**	**NO**	**Some-times**	**Don't Know**
16. Are the goals about the same for family members after their children have received an AAC device?				
17. Do you feel that you understand the needs and concerns of families before prescribing AAC devices? If **NO** or **SOMETIMES**, in what ways do you feel that you do not understand their needs (please list):				
18. Do you feel that you value and respect family members fully as members of the AAC decision-making team? If **NO** or **SOMETIMES**, in what ways do you feel that you do not fully value their participation as a team member (please list):				

Code No: ________

AAC Impact: Vendors

This questionnaire is designed to identify ways in which electronic AAC devices (e.g, Liberator, TouchTalker, Dynavox, System 2000, etc.) affect families. It will only take a few minutes to complete. Please answer the first few questions in the space provided. Then **check** (√) either **YES**, **NO**, or **SOMETIMES** after the next group of questions. *Thank you for your time and participation.*

Question	**YES**	**NO**	**Some-times**	**Don't Know**
1. Do family members that you work with have to receive training to learn how to use or maintain their children's AAC devices?				
If **YES** or **SOMETIMES**, does this result in family concerns (e.g., difficulty in finding child care, change in family routines, transportation, or other disruptions)				

If **YES** or **SOMETIMES**, what specific changes have you observed or have been reported?

2. Do family members have to take time daily to help children use or maintain their AAC devices?				

If **YES** or **SOMETIMES**, how much time (on the average)
________ minutes ________ hours

3. Do family members for whom you have prescribed AAC devices use them during social or recreational activities (e.g., going to restaurants, in church, etc.)?				
If **YES** or **SOMETIMES**, does this result in any concerns that are expressed by family members (e.g., difficulty in finding child care, change in family routine, or other disruptions)				

If **YES** or **SOMETIMES**, what specific concerns have family members expressed about AAC use in social or recreational settings? (please list)

4. Do you think that AAC devices place demands on family members?				

If **YES** or **SOMETIMES**, what specific demands do you think may affect family functioning (please list):

Question	YES	NO	Some-times	Don't Know
5. Do you think that AAC devices require changes in the home environment of families (e.g., rules, moving furniture)?				
If **YES** or **SOMETIMES**, what changes do you think must be made (please list):				
6. When family members must help a child use or maintain his or her AAC device, does this cause concerns for other children in the family (e.g, jealousy, anger, desire to be involved with device usage)?				
If **YES** or **SOMETIMES**, what concerns have been expressed to you (please list):				
7. Does the amount of time that a family member spend using or maintaining a child's AAC device cause concerns for the spouse or significant other?				
If **YES** or **SOMETIMES**, what concerns have been communicated to you (please list):				
8. Do family members have concerns about their child's AAC device use outside the home?				
If **YES** or **SOMETIMES**, what concerns have you observed (please list):				
9. Do family members feel that they need additional training to be able to more effectively use their child's AAC device?				
If **YES** or **SOMETIMES**, do you think that the service system (early intervention program or school system is typically able to provide the necessary training?				
10. Do changes occur in the family routines of family members if they receive additional training in the use of their children's AAC device?				
If **YES** or **SOMETIMES**, what changes would you expect (please list):				

Question	**YES**	**NO**	**Some-times**	**Don't Know**
11. Does family use or maintenance of their children's AAC device change the way that family members feel about themselves? If **YES** or **SOMETIMES**, in what ways does it change the way they feel (please list):				
12. Does family use or maintenance of their children's AAC device change the way that they about others in the family? If **YES** or **SOMETIMES**, in what ways does it change the way they feel (please list):				
13. Does family use or maintenance of their children's AAC device change the way that they feel about early intervention professionals or school personnel? If **YES** or **SOMETIMES**, in what ways does it change the way they feel (please list):				
14. Does family use or maintenance of their children's AAC device change the way that people in the community feel about them? If **YES** or **SOMETIMES**, in what ways does it change the way they feel (please list):				
15. Do family goals change once family members receive their child's AAC device?				
Do family members have higher goals or expectations for their child after receiving an AAC device? If **YES** or **SOMETIMES**, in what ways are they higher (please list):				
16. Do family members have lower goals or expectations for their child after receiving an AAC device? If **YES** or **SOMETIMES**, in what ways are they lower (please list):				

Question	YES	NO	Some-times	Don't Know
16. Are the goals about the same for family members after their children have received an AAC device?	☐	☐	☐	☐
17. Do you feel that you understand the needs and concerns of families before prescribing AAC devices? If **NO** or **SOMETIMES**, in what ways do you feel that you do not understand their needs (please list):	☐	☐	☐	☐
18. Do you feel that you value and respect family members fully as members of the AAC decision-making team? If **NO** or **SOMETIMES**, in what ways do you feel that you do not fully value their participation as team members (please list):	☐	☐	☐	☐

Code No: ________

AAC Impact: Multicultural Group

This questionnaire is designed to understand how AAC devices affect families. AAC devices are defined simply as "voice output communication aides which require training to use efficiently". It will not take much time to complete. Each set of questions will be introduced by several statements. You should **check** (√) either **YES**, **NO**, or **SOMETIMES** in the appropriate column after each question. You will also be asked to provide specific information about your thoughts, feelings, or experiences when answering some questions. *Thank you for your time and participation.*

Goals and expectations in using the AAC device. Family members and children may have goals or expectations before and after receiving AAC devices. These goals or expectations may or may not change once devices are actually received and used by the child and family. Think about the goals and expectations that family members might have for their children and his or her AAC device. Then answer the following questions:

1. Do you think family members might have goals or expectations for their children related to use of an AAC device before receiving the device?

YES	NO	Sometimes

If **YES** or **SOMETIMES**, what do you think the goals or expectations are for most family members?

2. Do you think the goals or expectations for children might change once family members receive the AAC device?

If **YES** or **SOMETIMES**, in what ways do you think they change?

Training in the use of the AAC device. As with any new electronic device, family members and children must often learn to use AAC devices appropriately. Sometimes training is required to use the AAC device. There may be **concerns** (**negative effects**) that result from *receiving* or *not receiving* training. There may also be **positive effects** that result from *receiving* or *not receiving* training. Think about both the positive and negative effects of *receiving* or *not receiving* training, and then answer the following questions:

3. If family members **receive training** to learn how to use or maintain their child's AAC device, are there any **concerns** that you think they might have prior to, during, or after the training?

YES	NO	Sometimes

If **YES** or **SOMETIMES,** what specific **concerns** might they have prior to, during, or after the training?

4. If family members **receive training** to learn how to use or maintain their child's AAC device, are there **positive effects** that they might have prior to, during, or after the training was provided?

If **YES** or **SOMETIMES,** what do you think these **positive effects** might be prior to, during, or after the training?

5. If family members **did not receive training** to learn how to use or maintain their child's AAC device, are there any **concerns** that they might have prior to or after receiving the AAC device?

If **YES** or **SOMETIMES,** what specific **concerns** might they have prior to or after receiving the device?

6. If family members **did not receive training** to learn how to use or maintain their child's AAC device, are there **positive effects** that they might have prior to or after receiving the device?

If **YES** or **SOMETIMES,** what **positive effects** might they have prior to or after receiving the device?

7. Assuming that the family has **already received some training** in the use of the AAC device, might any **additional training** have any effects on the child or family?

If **YES** or **SOMETIMES,** how might the **additional training** affect the child or family?

If **NO,** why would the **additional training not** affect the child or family?

Home responsibilities. Using AAC devices in the home may or may not affect the responsibilities of family members. Think about a child's AAC device and how it might affect the family responsibilities and routines. Then answer the following questions:

YES	NO	Sometimes
☐	☐	☐

8. Do you think that family members have to take time daily to help their child use or maintain the AAC device?
   If **YES** or **SOMETIMES**, how much time (on the average)?
   _________ minutes __________ hours

9. Do you think family members sometimes feel that their child's AAC device places demands on the family? ☐ ☐ ☐
   If **YES** or **SOMETIMES**, how might these demands affect the family?

10. Do you think that a child's AAC device might require changes in the home environment (e.g., rules, moving furniture)? ☐ ☐ ☐
    If **YES** or **SOMETIMES**, what changes might need to be made?

Family issues. Sometimes AAC devices used by a child will affect family members in the ways they behave toward one another. Think about ways in which a child's AAC device might affect the family as a whole. Then respond to the following questions:

11. Do you think that helping the child use or maintain his or her AAC device might affect other children in the family? ☐ ☐ ☐
    If **YES** or **SOMETIMES**, how might other children be affected?

12. Do you think that one spouse or significant other might be affected by the amount of time spent by the other spouse or significant other when using or maintaining the child's AAC device? ☐ ☐ ☐
    If **YES** or **SOMETIMES**, in what ways might he or she be affected?

Personal issues. Family members sometimes are affected personally when an AAC device is used by their child. Think about a child's AAC device and whether it might have an effect on a family member. Then answer the following questions:

13. Do you think family members use their child's device during social or recreational activities (e.g., going to restaurants, in church, etc.)?
If **YES** or **SOMETIMES**, might this have an effect on the family's quality of life?

YES	NO	Sometimes

If it **might have an effect on the quality of life**, please describe how:

When **family members do not use their child's AAC device in social or recreational activities**, what might be the reason?

14. Do you think that use or maintenance of a child's AAC device changes the way that a family member feels about him- or herself?

If **YES** or **SOMETIMES**, in what ways do you think they might feel differently?

15. Do you think that use or maintenance of a child's AAC device changes the way that a family member feels about others in the family?

If **YES** or **SOMETIMES**, in what ways might they feel differently about the family (please describe):

Outside the home. Using AAC devices in the community (e.g., at the store, when visiting friends) may sometimes have an affect on the family. Think about the ways in which a family member and their child might use the AAC device in community settings. Then answer the following questions:

16. Do you think family members might have concerns about a child's AAC device use in the community?

If **YES** or **SOMETIMES**, what specific concerns might they have?

YES	NO	Sometimes

17. Do you think that use or maintenance of a child's AAC device change the way that people in the community feel about the family member?
If **YES** or **SOMETIMES**, in what ways might they feel differently?

Working with professionals. In order to get a child's AAC device, family members have to work with one or more professionals. This may have been during assessment for or training in the use of the AAC device. Family members often have differing experiences in working with professionals. Think about a family's experiences with professionals. Then answer the following questions.

18. Do you think that professionals who work with family members to get a child's AAC device understand the family's needs and concerns regarding the device?
If **NO** or **SOMETIMES**, in what ways might professionals not understand the needs of the family members?

If **YES**, in what ways might they demonstrate an understanding of the needs of family members?

19. Do you think that professionals who work with family members to get a child's AAC device value and respect them as members of the team?
If **NO** or **SOMETIMES**, in what ways do you feel that they might not value the participation of family members?

If **YES**, in what ways do you feel that they might value their participation as team members?

20. Have your experiences with professionals changed the way that you feel about professionals who work with family members?
If **YES** or **SOMETIMES**, in what ways do you see professionals differently?